

**The Measurement of Behavioural Disturbance in
Dementia: An Evaluation of the Use of Activity
Monitors**

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PhD

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1992

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ABSTRACT

The recent advances in the miniaturisation of electronic activity monitoring devices have opened up new methods for the study of human activity. This thesis describes the application of such technologies to the measurement of behavioural disturbance in dementia. Many behavioural problems in dementia are manifested as changes in levels or patterns of activity. However, the validity and reliability of the use of activity monitors in the study of dementia had not been systematically addressed.

The first study carried out established that 80% of severe dementia hospital in-patients (22 subjects) would tolerate wearing an activity monitor for 72 hours. Evening activity levels in these patients were found to correlate with nurse ratings of "wandering and pacing" behaviour.

Two healthy elderly control samples were examined for activity level differences between seventy year olds (33 subjects: 70-72 years) and eighty year olds (25 subjects: 80-84 years). No significant differences were observed. A comparison of the severe dementia patients and controls showed significantly less activity in the dementia patients with a rise towards late afternoon whereas the control subjects showed peak activity in the morning.

The validity of monitoring activity as a measure of behavioural disturbance was assessed using a sample of mixed severity dementia patients living in the community (25 subjects). Cognitive function was assessed with the Mini-Mental State Examination and the Cognitive Assessment Schedule. Behavioural ratings were assessed using the Revised Memory and Behaviour Problem Check-list and the Behaviour Rating Scale of the Clifton Assessment Procedures for the Elderly. Collective ratings of behavioural problems were found to correlate highly (>0.5) with cognitive impairment. A rating of general agitation showed a significant correlation with afternoon activity measures, although other ratings of behavioural problems did not correlate significantly with activity.

A pilot drug withdrawal study was carried out. Behavioural change was assessed by direct observation of video filmed behaviour and compared to activity in 3 subjects and 3 controls. Inter-rater reliability of visual inspection of activity graphs was good and showed good agreement with filmed behaviour ratings.

Activity monitors are well tolerated by dementia patients and should prove most useful when used in conjunction with ratings of behavioural disturbance.

ACKNOWLEDGEMENTS

Firstly, I would like to thank the psychogeriatricians and general practitioners who allowed me access to their patients. I am particularly grateful to Dr Allan Jacques for his ideas, interest and enthusiasm for the research conducted with patients at the Royal Victoria Hospital. Many thanks are due to the ward staff at the Jardine Clinic and the Royal Victoria Hospital who kindly filled in rating scales and generally assisted me with this work.

Mike Glabus provided invaluable assistance with the activity monitor evaluation and wrote essential software for the analysis of the activity monitor data. Great thanks also are due to Dr John Starr who allowed me the benefit of his extensive knowledge of computing and statistics. I am grateful to the various members of the University of Edinburgh Department of Psychiatry who offered intellectual and emotional support by way of coffee room consultations through out the three years of this work. Mrs Brenda Thomas has been particularly helpful with providing access and assistance with computing facilities. Dr Geoff Hide has been a marvellous source of encouragement and useful advice and has been invaluable during the writing up of this thesis.

I would like to thank Professor Lawrence Whalley, my primary supervisor and Professor Eve Johnstone my secondary supervisor for their advice and encouragement.

The activity monitors used in this research were purchased with grant 979 from the Scottish Hospital Endowments Research Trust. I was supported during this course of study by the Walter Smith Kay Research Scholarship from the University of Edinburgh Faculty of Medicine.

DECLARATION

I declare that this thesis and the results reported in it are all my own work.

Jacqueline A Hide

CHAPTER 1

An Overview of the Literature on Behavioural Disturbance in Dementia and the Measurement of Activity.

1. Definition of dementia

Dementia is the term used to describe a group of diseases in which memory impairment is the main feature. Lishman defines dementia thus

"Dementia is an acquired global impairment of intellect, memory and personality but without impairment of consciousness." Lishman (1978).

A more detailed idea of what dementia entails may be obtained from the diagnostic criteria for dementia listed in the Diagnostic and Statistical Manual (DSM-III-R) of the American Psychiatric Association (1987). This includes an impairment in short and long term memory and at least one of the following: impairment in abstract thinking, impaired judgment, other disturbances of higher cortical function. These disturbances must significantly interfere with work, usual social activities or relationships with others and must not occur exclusively during the course of delirium. Finally dementia may only be assumed if the presence of a specific dementia is found through medical investigations, or by ruling out any other possible diseases.

This recognition of the dementia syndrome and specific types of dementia has come about relatively recently in the history of psychiatry and medicine. Rosen's (1961) essay researching the history of dementia points out that the term dementia stems from the Latin word "dementatus" meaning to be crazed or out of one's mind. The confusion of insanity, mental handicap and dementia as we know it, persisted into the 18th century. Mahendra (1984) comments that this state of affairs is not surprising

since the number of cases of old age dementia, must have been very low considering the short life expectancies. The relationship between memory loss and melancholy was recognised centuries earlier, contributing to the slow evolution of understanding dementia. By the early 19th century it was generally believed that the cognitive impairment of old age was precipitated by organic impairment but no distinction was made between acute injury or infection and the chronic decay, now associated with true dementia.

No real advancement in the understanding of the aetiology dementia could come about until it was recognised that dementia existed in several forms. In the late 19th, early 20th century such investigators as George Huntington, Arnold Pick, and Alois Alzheimer described cases typical of the types of dementia to be later named after these authors. Griesinger recognised a disease of the cerebral arteries to cause dementia, in 1845, and Kraepelin and Alzheimer distinguished this type of dementia, now commonly referred to as multi-infarct dementia (MID), from senile dementia of the Alzheimer type or Alzheimer's disease (AD) in 1898. This early clinical description of a typical case of senile dementia is taken from Emil Kraepelin (1906) "Lectures on Clinical Psychiatry".

"The patient gradually became forgetful, was confused as to time and did not even know her way about her own house, could not remember whether she had had her meals or not, and mistook people. ...She also showed a certain degree of restlessness. The patient became irritable, peevish and distrustful, would not go to bed in the evening, and got up early before dawn. She rummaged about aimlessly, wanted to go out, could no longer do her work in an orderly way and had a capacious appetite."

This excerpt constitutes about a fifth of the case description which mostly dwells on the impairment of the patient's memory, which leads Kraepelin to conclude:

"The most prominent feature of the case is evidently the almost complete failure of the *power* to retain impressions, which far exceeds anything we have observed in other forms of disease."

Dementia was considered an irreversible syndrome until the 1960s when some presentations of dementia were concluded to be treatable; for example, normal pressure hydrocephalus. The irreversibility of dementia is still seen by some workers as an important part of the concept, thus reversible dementias are often referred to as secondary dementias. Acute confusional states mimic dementia but are usually recognised by their short duration and the presence of causal medical conditions such as urinary tract infection or drug intoxication.

The work on the identification of dementia sub-types continues, with the emphasis on neuroanatomical pathology rather than clinical symptom presentation. The latter approach has proved problematic in the study of the dementias due to the diversity of behavioural changes seen in different patients. A more fruitful approach has been to identify biological markers for particular types, such as the presence of neurofibrillary plaques and tangles in Alzheimer's disease, or the presence of small brain infarcts detectable by computed tomography (CT) scans. In vivo techniques, such as the use of brain scans, together with other clinical evidence can be used to identify some clear cut cases of a dementia sub-type, after which the investigation into different symptoms presentations can proceed (Riege and Metter, 1988).

Conclusion. The term dementia defines a group of patients with distinctive clinical symptoms and signs. Whilst behavioural changes are an important part of the clinical syndrome of dementia, they do not systematically reflect the neuropathological and neurochemical differences found between the various types of dementia.

2. Introduction to behavioural disturbance in dementia

The study of behavioural disturbance in dementia has only been seriously undertaken since the mid 1980s, possibly because it has been seen as secondary in nature to cognitive deficit. It is estimated that 5% of people over 65 and possibly 20% of those over 80 years of age are likely to suffer from some form of dementia (Gurland and Cross, 1982). The proportion of elderly to young people is increasing as is the absolute number of elderly citizens in the wealthy countries of the world. These figures have ensured that all aspects of the dementias have received increasing attention, especially behaviour problems which seem more amenable to treatment than the cognitive deficit has proved so far.

Over the course of a dementing illness any or every aspect of a patient's behaviour may change to some degree. Most of these behavioural changes will involve an increasing deficit in behaviour, including a decline in the ability to perform mental, physical and social requirements. Some new behaviours may become apparent or other behaviours may be performed with increased frequency. Any behavioural change is likely to be unpleasant to close relatives and carers of dementia patients, but the change in social behaviours are often those that cause the greatest distress.

The point at which a behavioural change becomes a behavioural "disturbance" is when the behaviour becomes disturbing or distressing. This is usually determined by the needs of those living or working with the patient or when the patient themselves appears to be distressed. The behavioural changes manifested in the dementias vary considerably between patients with the same condition and even within patients at different stages of the disease. This variety in types of behavioural change may be due to the existence of several possible sources from which disturbed behaviour might

arise.

3. Causes of behavioural disturbance in dementia

An important initial consideration is that patients may be suffering from concomitant medical complaints which can cause disturbed behaviour. O'Connor (1987) conducted a retrospective analysis of admissions to an acute psychogeriatric ward for disturbed behaviour (the particular behaviours for which patients were admitted are not cited). 70 dementia patients (70% Alzheimer's disease, 6% multi-infarct dementia, 22% alcoholic dementia) with varying disease severity, underwent medical and psychological examination. 8.5% of the patients were discovered to be suffering from drug-induced delirium, superimposed on dementia. 34.4% were found to have an active physical illness that required therapy and 11.4% had concurrent psychiatric illness. O'Connor (1987) reports that in only 39% of his sample was progressive dementia alone an adequate explanation for the behaviour disturbance.

Cumming et al (1982) reported on the episodic nature of behavioural disturbance in elderly long-term care residents. They suggested that episodes of behavioural disturbance (on average about 100 days) may be linked to dramatic fluctuations in physiological states. Although these residents were not assessed for the presence of dementia or cognitive impairment, it is likely that dementia sufferers are as prone to biological-behavioural fluctuations as the sample examined by Cumming et al (1982).

Even after excluding concurrent illness, the aetiology of behavioural problems in dementia is highly complicated. Disturbed behaviour may be caused directly, by the degeneration of brain tissue, or via more complex routes, such as a normal or

abnormal response to a confusing, misperceived environment, generated by impaired cognitive functioning.

Before attempting a detailed definition of behaviour disturbance in dementia it is important to consider whether behaviour disturbances can be viewed as a single set of events, or whether different types or presentations of dementia show distinct patterns of behavioural change.

3.1. Location of neural degeneration and type of dementia

There is substantial evidence of a direct link between specific areas of brain lesion and particular behavioural changes (Brooks, 1988; Lishman, 1987). The evidence to link antisocial or disinhibited behaviours (including violence) to frontal lobe dysfunction is particularly convincing (Kandel and Freed, 1989; Heinrichs, 1989). Pick's disease has been distinguished from other dementia sub-types by typical neuropathological features. These are the ballooning of the affected cell bodies, with argentophilic inclusions (Pick's bodies), and by the pattern of brain atrophy, namely in the frontal and temporal lobes. Changes in character and personality are often seen *before* memory impairment is detected, unlike other dementias (Chang Chui, 1989).

Neary et al (1988) in the UK and Gustafson et al (1987) in Sweden have suggested there is another type of dementia that presents itself in a similar way to Pick's disease, but which has microscopic cell changes which are different from both Pick's disease and Alzheimer's disease. Regional cerebral blood flow studies (Risberg et al, 1987) and single photon emission tomography (Neary, 1987) show reduced brain activity in the frontal and prefrontal regions in these patients leading to a designation of Dementia of the Frontal lobe Type (DFT). In these patients social breakdown and progressive personality change are the most prominent early features of disease. However, frontal

lobe dysfunction may also be present to some extent in Alzheimer's disease due to general brain degeneration (Erkwoh et al, 1989) and as small infarcts in cases of multi-infarct dementia.

De Leon, Potegal and Gurland (1984) hypothesised that wandering in Alzheimer's disease may be due to lesions in the parietal lobe due to its association with spatial orientation. They identified a group of 5 out of an initial sample of 21 Alzheimer's disease patients as "wanderers", who showed greater impairment on tests of parietal function, such as clock reading. However, other authors have suggested that psychometric tests measuring parietal deficits such as the Kew test (Hare, 1978; Gilleard, Spain and Carroll 1987) and clock drawing (Sunderland et al, 1989; Wolf-Klein et al, 1989) are an excellent measure for global severity of dementia or Alzheimer's disease, with no mention of specific problems. It is difficult to set up or draw conclusions from such studies due to the small numbers of subjects with specific behavioural problems and lack of certainty that particular psychometric tests are subserved by specific brain areas.

Forette et al (1989) found the differential diagnosis of dementia can now achieve 95% reliability when the DSM-III-R criteria, and the results of the Modified Ischemic Score and CT scans are considered together. As discussed above, fairly rare sub-types of dementia have been identified which show distinct behavioural differences and clinical observation suggests that there may be some differences in the behavioural changes associated with the two most common forms of dementia, Alzheimer's disease and multi-infarct dementia.

The Ischemic Scale, based on the original clinical observations of Slater and Roth (1969) was devised by Hachinski et al (1975) to distinguish multi-infarct dementia

from Alzheimer's type dementia. It attributes greater "nocturnal confusion", "emotional lability" and "preservation of personality" to multi-infarct dementia patients. This widely used scale has been the subject of various investigations to assess the validity of its individual items (Rosen et al, 1980; Loeb, 1980; Gustafson and Nilsson, 1982; Loeb and Gandolfo, 1983; Molsa et al, 1985; Erkinjuntti, 1987). While Molsa et al (1985) found all three of these items held validity for distinguishing multi-infarct dementia from Alzheimer's disease, the other five studies are less positive. Of these studies, none found "nocturnal confusion" to be a useful item and only one found "personality preservation" somewhat discriminating (Erkinjuntti, 1987). The item "emotional lability" was found useful by three studies (Rosen et al, 1980, Gustafson and Nilsson, 1982; Erkinjuntti, 1987). A major problem with these studies is distinguishing multi-infarct dementia from Alzheimer's disease without using the very criteria one wishes to test the validity of, and also avoiding the confusion and unreliability of the mixed diagnosis (both diseases present).

Rothchild (1941) compared clinical signs in 31 patients with "senile dementia" and 29 patients with "arteriosclerotic psychoses" and reported a higher incidence of "depression", "hypochondriacal-like symptoms" and more "explosive emotional outbursts" in the probable multi-infarct dementia group. Three more recent studies by Bucht and Adolfsson (1983), Cummings et al (1987) and Swearer et al (1988) found no major differences in prevalence of behaviour problems between the two dementia types, although Bucht and Adolfsson (1983) found some cognitive characteristics distinguished the multi-infarct dementia from the Alzheimer's disease group. Meyer-Knoig (1984) detected greater "emotional incontinence" and "depression" in dementia patients with clinical evidence of arteriosclerosis although this might not necessarily equate with multi-infarct dementia very closely (Molsa et al, 1985).

The evidence which points to greater "emotionality" as a characteristic of multi-infarct dementia, can possibly be explained by the fact that there is more early sub-cortical involvement in this type of dementia. Ballard, Mohn and Patel (1991) found "getting lost outside the home" to be more common in Alzheimer's type dementia than vascular dementia, although they had 56 Alzheimer's disease patients to only 10 vascular dementions in their sample. The authors claim this is consistent with reports of greater atrophy of the parietal and temporal lobes observed in Alzheimer's disease. The location of brain degeneration is an important factor for behavioural change and this is still not easily predicted by the differential diagnosis of dementia.

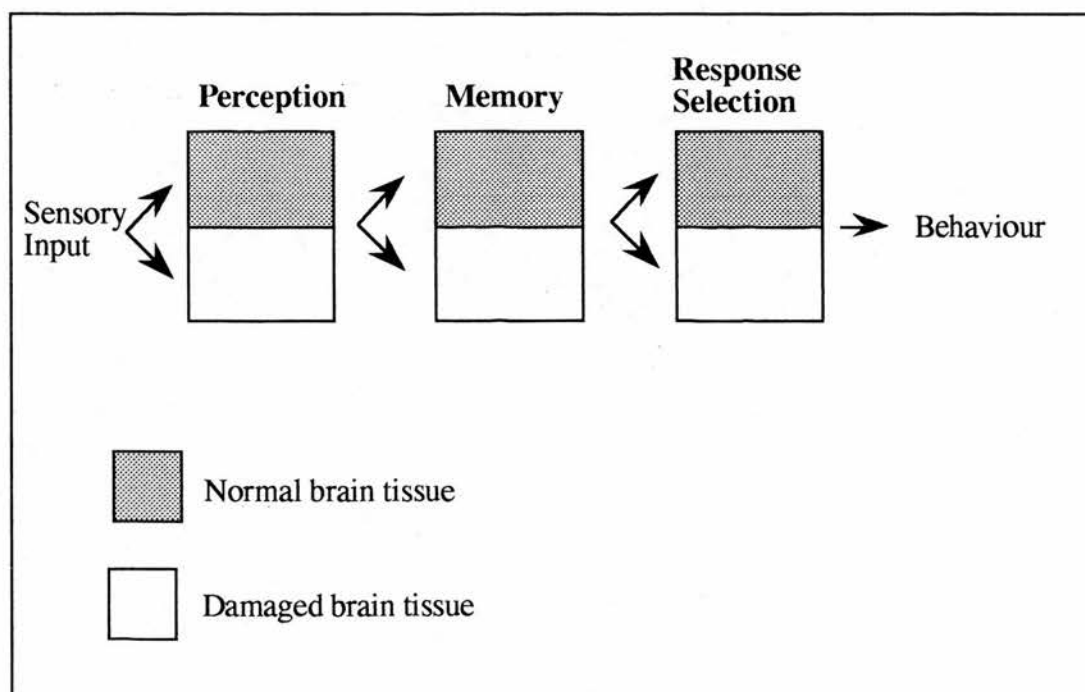
3.2 A multi-causal model of behaviour disturbance in dementia

Behaviour problems may arise through a more indirect route, in response to an abnormally perceived environment. Such perceptions may arise from forgetting information which was originally interpreted correctly, or through dysfunctional sensory collection (poor eye sight for example) or through errors in sensory processing (hallucinations). These responses may be generated by normal psychological processes or psychological processes damaged by brain degeneration, or result from the inter-play of the two. These events are summarised by the model in figure 3.2.1. The behaviour resulting from sensory input is dependent on three stages of processing, perception, memory and response selection. Brain damage in any or all of these areas may result in altered behaviour.

As dementia progresses greater neural damage occurs and behaviour changes may increasingly become the direct result of damaged tissue. The type of behavioural disturbance may thus vary as the disease progresses. For example, in the very early stages of dementia, a patient may be distressed by their recognition of their declining mental abilities. Some patients may be aware that dementia is a fatal condition and

suffer the attendant feelings of denial, anger, depression and grief, which have been characterised as the psychological processes accompanying dying (Kubler-Ross, 1969). At this stage in the disease close relatives may be unsure how to react to the patient and family relationships may be severely disrupted (Cohen, Kennedy and Eisdorfer, 1984; Silliman, 1988). Later in the disease frontal lobe degeneration may cause the patient to behave in a bizarre manner and yet not realise they are behaving so, due to behavioural disinhibition.

Figure 3.2.1 A model depicting potential sources of abnormality in the processing of environmental stimuli and reaction behaviour in dementia sufferers.



This multi-causal model is vindicated by detailed behavioural analysis of particular behavioural problems. The single behaviour to have received the most attention and

investigation is that of "wandering". "Wandering" comprises a number of distinct behaviours and motivations. Synder et al (1978) identified three types of wandering in 22 dementia patients: overtly goal directed / searching behaviour, overtly goal directed / industrious behaviour and apparently non-goal directed behaviour. The authors also found that there were three different psychosocial factors that predisposed individuals to wander. Monsour and Robb (1982) found different premorbid life styles and coping styles between wanderers and non-wanderers, whilst Dawson and Reid (1987) found hyperactivity to be a major factor differentiating wandering from non-wandering patients.

Fairburn and Hope (1990) sought to define types of wandering by giving the carers of 29 wandering patients an extensive semi-structured interview. The authors report a descriptive typology of wandering derived from these interviews, which falls into 9 separate categories. The confusion surrounding different uses of "wandering" leads them to suggest that the term is so general it should not be used. Their paper represents one of the first attempts to analyse closely exactly what constitutes a problem behaviour in dementia and the results point to a complex set of behaviours and causes even within this one term.

Hussain (1980; 1982; 1984) has well documented the view that behaviour modification techniques can be effective in reducing some patients' behaviour problems. Rader (1987) showed that a change in care staff's behaviour could effect a significant reduction in "problem wandering". Similarly Rosenberger (1983) found that by encouraging nursing staff to use differential social reinforcement they could dramatically reduce kicking, banging, self exposure, throwing dishes and pushing objects into others in institutionalised geriatric patients.

Unfortunately these studies do not state the degree of cognitive impairment in their subjects and it could be that the best results are achieved with the less cognitively impaired. Despite this proviso, the fact that such behavioural change can be brought about in some patients suggests that some problems are the result of poor interpretation or remembering of environmental and social behaviour cues. Hallberg, Norberg and Erikson (1990) compared 37 vocally disruptive dementia patients with matched, ward dementia controls. They found vocally disruptive behaviour to be related to physical dependence, disorientation and the presence of delusions and hallucinations. The authors suggest that vocally disruptive behaviour results from a combination of brain damage affecting perception and environmental factors interacting to distress the patient.

Whilst this multi-causal approach may facilitate treatment strategies for individual patients it provides little information for predicting either the likelihood of behaviour problems developing or their duration. Behaviour problems in dementia have been shown to be an important cause for admission to long term care (Argyle, Jestic and Brook, 1985; Sanford, 1975). Information on prevalence and incidence of behaviour problems is therefore important for planning future care facilities.

Behavioural problems are a major cause of stress (Pruchno and Resch, 1989; Chenoweth and Spencer, 1986; Gilleard and Watt, 1982) and even illness (Goldman and Luchins, 1984; Morris, Morris and Britton, 1988) in the carers of dementia patients. Information on the nature and duration of behaviour problems could greatly assist the counselling of burdened carers (Rabins, Mace and Lucas, 1982). Caregiver satisfaction plays a crucial role in the implementation of the Government policy to retain long-term care patients in the community as long as possible.

Conclusion. Behavioural change in dementia can arise from numerous sources. It is the result of interactions between faulty brain operation and properly functioning psychological processes. As dementia progresses abnormal behaviours are increasingly likely to result directly from brain degeneration. A behavioural change becomes a problem behaviour when it is perceived as disturbing either to the patient or those around the patient.

4. Prevalence of behavioural problems in dementia and their relationship to disease severity

The demarcation of that group of behaviours which are recognised as behavioural problems in dementia has advanced with the recent publication of a number of prevalence studies. There have been over 32 studies which give some insight into the prevalence of behaviour problems or personality change in dementia since 1975. These studies cover various populations of elderly patients, although all have been confirmed to have cognitive impairment.

Sanford (1975) Argyle, Jestic and Brook (1985) and Ballinger et al (1982; 1988) recorded the behaviours problems of new admissions to psychogeriatric wards. Mann, Graham and Ashby (1984) Zimmer, Watson and Treat (1984) and Cohen-Mansfield, Mark and Rosenthal (1990) have recorded the problems of cognitively deteriorated nursing home residents. Gilleard and Watt (1982) and Greene et al (1982) have investigated what the caregivers perceive to be problems with attenders at day hospitals and Reisberg et al (1987) took a similar population and reviewed problem behaviours recorded in the case notes of such patients. More recent work,

designed specifically to look at the prevalence of behaviour problems has dealt mainly with community residing patients (Rubin et al, 1987a; 1987b; Drevets and Rubin, 1989; Teri et al, 1988; 1989; Swearer et al, 1988) or used multiple sources (Cooper, Mungas and Weiler, 1990; Patterson et al, 1990; Baumgarten et al, 1990).

Not surprisingly, the diagnoses of the subjects in these studies vary somewhat, with samples of Alzheimer's disease, multi-infarct dementia or mixtures of dementia types. The criteria for dementia and differentiating dementia sub-types ranging from basic (cognitive impairment only) to sophisticated (eg DSM-III-R or National Institute of Neurologic and Communicative Disease and Stroke / Alzheimer's Disease and Related Disorders Association). The severity of dementia is not reported by many researchers and even in the cases that do state the dementia severity, various different criteria are used.

The types of behaviour recorded have varied between studies. Some researchers concentrated exclusively on psychotic symptoms (Berrios and Brook, 1985; Mayeux et al, 1985; Merriam et al, 1988; Drevets and Rubin, 1989; Jaben et al, 1992), others concentrated on personality (Petry et al, 1988; 1989; Siegler et al, 1991) while many other authors incorporated a mixture of symptoms. A large variety of behaviours have been measured between these studies. The definitions used for ostensibly the same behavioural problems may also vary considerably between studies, but most often exact definitions of terms are not provided. The list in table 4.1a represents a collection of behavioural terms reported in studies on behavioural disturbance in dementia. An attempt has been made to group behaviours into five broad categories of (1) psychotic-type; (2) personality change / aggression; (3) wandering / overactivity; (4) passive; (5) miscellaneous.

Table 4.1a. List of behavioural terms used in the studies of behavioural problems in dementia.

(1) paranoid labile	suspicious anxious	delusions fearful	hallucinations
(2) personality conflict agitated personality change catastrophic reaction	restless unco-operative violence rage behaviour	irritable critical verbal aggression violence against others	self-centered demanding shouting violence against self
(3) pacing getting lost sleep disturbance	wandering insomnia	day wandering overactivity	night wandering stereotyped behaviours
(4) passive	withdrawn	underactive	depression
(5) vulgar bizarre behaviour sexual disturbance	unhygienic changed diet faecal smearing	incontinent bad language falling	refusal to eat hoarding

A large source of variance comes from the method of recording when a particular behaviour is present. The majority of studies do not report how frequently a behaviour has to occur before it is considered present. The frequency with which a behaviour occurs may be crucial in determining whether the carer perceives the behaviour to be a problem or not. Burns, Jacoby and Levy (1990) recorded whether behaviours occur in three categories, rarely or never, sometimes, or often. Patterson et al (1990) recorded behaviours if they occurred in the week preceding the interview. Baumgarten et al (1990) reported behaviours occurring at least "sometimes" in the previous week.

Teri et al (1989) reported the results for behaviours occurring more than twice in the last week. This may in part explain the relatively low prevalence rates reported by Teri et al (1989) in this study, both compared to other authors and compared to their other studies using different methods of assessing behavioural problems.

In order to compare the results of prevalence studies, each study must provide information on the nature, extent, frequency and duration of the behaviours measured. "Wandering" is one of the most frequently measured problems in these studies, probably because it is an easily observed behaviour. However, as Fairburn and Hope (1990) discovered, "wandering" does not constitute a single concept. The problems of comparison between studies are well illustrated by comparing the prevalence rates from a number of studies which measure wandering type behaviour, listed in table 4.1b.

Table 4.1b. A comparison of prevalence rates for wandering-type behaviour in studies with varying frequencies of reporting and severities of dementia.

Study	Frequency	Description of Behaviour	% Patients with Behaviour
Ballard et al (1991)	present/absent	getting lost outside getting lost inside	36.9 28.3
Baumgarten et al (1990)	"sometimes" in past week	wandering pacing	10.4 27.1
Burns et al (1990)	"sometimes" or "often"	wandering-mild dementia moderate severe	0 10.2 27.0
Chenoweth et al (1986)	present/absent	wanders off	9
Cooper et al (1990)	present/absent	wandering-mild dementia moderate severe	11.9 23.5 37.7
Mann et al (1984)	present/absent	wandering-mild/mod dementia severe	4 11
Patterson et al (1990)	present previous week	wandering	12
Rabins et al (1982)	present/absent	day time wandering	59
Teri et al (1988)	present/absent	wandering mild dementia moderate severe	18 22 50
Teri et al (1989)	at least twice previous week	wandering-moderate dementia overactive/pacing	5 16
Teri et al (1990)	present/absent	wandering	23

The two studies which differentiate between wandering and pacing show pacing to be the more common phenomenon. It can be assumed that since the remaining studies did not measure pacing separately, it was included in the term "wandering". This effectively increases the number of behaviours being assessed under one item and will

inflate the prevalence figures for "wandering". However, it is possible to extrapolate an approximate prevalence figure for wandering (including pacing) in a moderately severe dementia sample of around 20%.

It is of particular interest that the studies which measure "wandering" separately for patients with differing severities of dementia show an increase as the disease progresses. This finding is not ubiquitous since a number of studies have not found a link between an increase in all or some behaviour problems and disease severity or cognitive decline. A survey of the studies which have examined the link between disease severity or cognitive decline is presented in table 4.2.

Most of the studies listed in table 4.2 found that behavioural problems became more prevalent in samples of patients as global dementia severity or cognitive deficit worsens. Teri et al (1989) did not find this relationship with any particular behaviour, or all of the behaviours together. This may be attributable to the fact that the sample is of mild to moderate patients only and therefore too homogeneous to show any weak relationships. Ballard, Mohan and Patel (1991) also did not find a significant association between "getting lost outside", or "getting lost inside" the house and disease severity. As they point out, their behavioural definition is specific and it may be that other aspects of "wandering" do show a positive increase with dementia severity. It is likely that behaviours which result from neural degeneration will show a roughly linear relationship with disease severity, since brain atrophy becomes more pronounced as dementia progresses. More indirect problem behaviours, such as those arising from mis-remembering, may have a more complex association, missed by correlational techniques. This might explain why the correlation coefficients, although significant at conventional levels, are fairly small, explaining only a small proportion of the variance.

Table 4.2. A summary of studies investigating the relationship between behavioural problems and cognitive decline or dementia severity.

Study	Sub- jects	Diagnosis	Assessment of cognition/severity	Significant correlations with dementia severity or cognitive decline and presence or number of behavioural problems.
Mayeux et al (1985)	62	DAT	BDRS & Cognitive tests.	Test performance & BDRS score with "psychotic symptoms".
Rubin et al (1987)	44	SDAT	CDR	Dementia severity with number of behaviours per patient and number of patients with any behaviour.
Ballinger et al (1982) + (1988)	100	SDAT or MID	CAPE I/Q score.	None. Different patients had behavioural problems one year later but the overall number of problems was the same for the group.
Merriam et al (1988)	175	DAT	BIMCT	BIMCT score with hallucinations (but not delusions or paranoia).
Teri et al (1988)	127	AD	MMSE & BDRS	Dementia severity with number of behaviours per patient and number of patients with any behaviour. Specifically: MMSE score with agitation, hygiene, wandering and incontinence. BDRS score with hygiene, wandering and incontinence.
Teri et al (1989)	56	DAT	MMSE & DRS-C	None. (Only mild or moderate patients included)
Drevets et al (1989)	162	SDAT	CDR & BDRS	CDR with "psychotic symptoms" in mild and moderate patients only. (No correlation with severe dementia and presence of symptoms).

Table 4.2. continued.

Study	Sub- jects	Diagnosis	Assessment of cognition/severity	Significant correlations with dementia severity or cognitive decline and presence or number of behavioural problems.
Petry et al (1989)	30	AD	MMSE	MMSE score with excitability trait only.
Swearer et al (1989)	126	AD+MID	CDR & own scale MMSE+BIMCT	Dementia severity with presence and severity of behaviours. (violent,bizarre,paranoid & incontinent) Violence with MMSE and BIMCT cognitive scores.
Cooper et al (1989)	680	Probable AD	MMSE	MMSE score with number of behaviour problems per patient, also with presence of anger, agitation, wandering and psychotic behaviours.
Baumgarten et al (1990)	50 + 46	dementia & AD	MMSE	Sample 1. None Sample 2. "Clinical severity" with number of behaviour problems.
Patterson et al (1990)	34	AD	MMSE & CDR	MMSE score with delusions & hallucinations. But CDR score not linked with delusions and hallucinations.
Burns et al (1990)	178	Probable AD	Camdex & CDR	Most behaviours increasingly common as disease progresses, however psychotic symptoms not linked to dementia severity.
Ballard et al (1992)	92	dementia	Camdex	None. (Only wandering examined).

Abbreviations: AD - Alzheimer's Disease. (S) DAT- (Senile) Dementia Alzheimer Type. MID-Multi-Infract Dementia.
BDRS- Blessed Dementia Rating Scale. CDR- Clinical Dementia Rating. CAPE-Clifton Assessment Procedures for the
Elderly. BIMCT- Blessed Information, Memory, Concentration Test. MMSE- Mini-Mental State Exam. DRS-C- Dementia
Rating Scale-Coblentz.

Cooper, Mungas and Weiler (1990) speculate that other factors, such as concurrent medical / psychiatric disorders and environmental factors may be more important influences on behaviour than cognitive status.

Conclusion. Prevalence figures for behavioural problems in dementia vary considerably depending on the criteria used. Important considerations include: type of dementia and population sampled; severity of disease; types of behaviours measured and specific definitions of terms used; frequency and duration of problems. "Wandering" is one of the most commonly measured behaviours. It is recorded in about 20% of dementia patients suffering from moderate dementia. In general, the broader the set of behaviours measured as "problems", the greater the percentage of the sample who will show at least one problem. One study which included items on memory loss (Teri et al, 1989) found every patient to suffer from at least one "problem behaviour". This is because memory loss is intrinsic to the definition of dementia.

The frequency of any one type of behaviour problem and the number of problems per patient increases as dementia becomes more severe. However, the relationship is complicated and other pathological and environmental factors may be as good or better predictors of behavioural disturbance.

5. Rating scales for assessing behaviour problems in dementia

The variability of behavioural changes manifested during the course of a dementing illness has hampered agreement between authors as to what actually constitutes a behaviour problem. Another confounding factor is that in early work the groups of

behaviours examined have varied with the aim of the research. Much of the early information on behaviour problems came from clinical descriptions and drug treatment studies. Sunderland and Silver (1988) reviewed 20 studies using neuroleptics to treat behaviour problems in dementia up to 1986. Of these studies all used some kind of rating scale, many more than one scale. The most frequently used measures of behaviour were the Nurses Observation Scale for In-patient Evaluation (NOSIE, Honigfeld et al 1966) in 9 studies and the Brief Psychiatric Rating Scale (BPRS, Overall and Gorham, 1962) in 7 studies. The validity of these general psychiatric rating scales is questionable when used for dementia behavioural changes and this has been recognised by many authors who appended other methods of assessment such as examining nursing records or interviewing carers. The lack of valid, reliable scales for these studies meant that much of the work is difficult to replicate.

The definition of behaviour disturbance in dementia is moulded by the items present in rating scales, hence pinpointing a common core of behaviours may assist in the theoretical description of the phenomena. The different aims of researchers has quite properly led to the development of somewhat different methods and, more importantly, content of measurement (ratings of behaviour tend to be most commonly used). Drug treatment studies frequently wish to assess the global impact of a treatment on the disease and early rating scales have reflected this, measuring both cognitive and behavioural changes.

Blessed, Tomlinson and Roth's (1968) important work established a link between the number of senile plaques found in the dementing brain and various measures of behavioural change. They developed an assessment schedule to measure: (1) cognitive deficit -the Information, Memory and Concentration Test, in which questions were put to the patients, (2) performance of everyday activities and (3)

changes in habits, personality, interests and drive, for which ratings of change were obtained from carers. Cognitive deficits can be directly measured by testing the patients' mental ability with traditional psychometric tests. As the common pattern of cognitive deterioration has been elucidated (e.g. Erkinjuntii 1986) tests have been developed to pick up small changes in performance in dementia patients specifically (Ritchie, 1988). These different approaches to assessment distinguish cognitive decline from other behavioural changes.

Having said this, some authors have used relatives' ratings of cognitive change as a measure (Jorm, 1989). The obvious disadvantages of this method are that ratings are more subjective and less sensitive to change than direct assessment. They may be of use, however, at the extremes of dementia, when very mild cases may not show as abnormal compared with population norms, or when patients have such severe dementia they cannot communicate to be tested. The differentiation of functional and other behavioural deficits is more complicated since observer / carer ratings are the most common measure of all these behaviours.

A number of geriatric behaviour rating scales have been developed for use with treatment studies, measuring multiple deficit domains. The Stockton Geriatric Rating Scale (SGRS) was first published by Meer and Baker (1966), revised by Pluchick (1970) to the Geriatric Rating Scale (GRS) and re-revised for a British population by Gilleard and Pattie (1977) to form the Behaviour Rating Scale of the Clifton Assessment Procedures for the Elderly (CAPE). The latter authors honed the scale down to 20 items which fall into four categories, physical dependency, social disturbance, apathy and communication problems. Other widely used large scales include the Physical And Mental Impairment of Function Evaluation (PAMIE, Gruel, Linn and Linn 1972), the Dementia Rating Scale (DRS, Lawson, Roden and Dykes

1977), the Sandoz Clinical Assessment: Geriatrics (SCAG, Shader, 1974) the Psychogeriatric Dependency Rating Scale (PDRS, Wilkinson and Graham-White 1980), and the Alzheimer's Disease Assessment Scale (ADAS, Rosen, Mohs and Davis, 1984).

Gilleard (1984) reviewed 28 scales assessing behavioural impairment, including 7 studies in which factor analyses had been conducted on the responses to the items in the scales. Of the 7 scales, 2 are derived from the SGRS (the GRS and the Shortened Stockton Rating Scale, SSRS, Twining and Allen, 1981) but since all three scales give slightly different factors it seems appropriate to leave them in the analysis. Six factors emerge in all, although no scale purports to have all six.

The two factors which are common to all 7 scales are a factor of physical disability / infirmity or deficits in acts of daily living and a factor of "social disturbance" (Gilleard, 1984), variously called emotional control, aggressiveness, social impairment, psychological agitation or anti-social disruptive behaviour. The other factors are cognitive impairment, apathy or withdrawal, communication and mood.

A slightly different view comes from Reisberg et al (1987) who took behaviours from the nursing reports of Alzheimer's disease patients and culled other items from the literature to produce a set of "potentially remediable" behaviour problems. This is an important distinction since it leaves out many of the behavioural changes referred to as functional deficits, such as an inability to feed or clothe oneself. This distinction may need to be made separately for individual patients. A behaviour such as "incontinence" may be a functional deficit in some patients and a social problem in others, that is, the latter may be capable of toilet skills but use "incontinence" to obtain extra attention from the caregiver. The measure designed from this work, the

Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) measures 7 areas of behaviour : delusions, hallucinations, activity disturbance, aggression, diurnal rhythm disturbance, affective disturbance and anxieties and phobias, with 25 items.

Greene et al (1982) obtained ratings of behaviour and mood problems in 38 dementia patients living in the community from their carers. A principal components factor analysis of behaviours described resulted in three factors: apathetic-withdrawn, active-disturbed and mood disturbance. The work of Rubin et al (1987a) reflects similar behavioural categories after factor analysis and assignment to "clinically useful groups". The items used include those from the Blessed Dementia Scale and open ended questions about personality changes, which were categorised into 6 headings. The three most common types of behavioural change are described as passive behaviours, agitated behaviours and self-centered behaviours.

Teri et al (1992) have conducted a factor analysis on 64 behavioural items, 30 taken from the Memory and Behaviour Problem Check-list and 34 other relevant behaviours added by the authors. After adapting it to enhance reliability and validity the final scale (the Revised Memory and Behaviour Problem Check-list) contains 24 items which fall into 3 subscales: depressive, disruptive and memory related disorders.

Baumgarten, Becker and Gauthier (1990) have contributed to the narrowing down of the definition of behaviour problems and developed the "Dementia Behaviour Disturbance Scale" to specifically measure behaviour problems alone and not cognitive, affective and functional impairments. The ratings are based on observable behaviour only and reporting is based on a Likert-type 5 point scale, to assess the

frequency of behaviour. Mungas et al (1989) have taken this refining process one step further and only included the disruptive behaviours of physical aggression, verbal aggression, agitation and wandering in their Disruptive Behavior Rating Scales. This scale had been developed specifically for clinicians who need to make accurate detailed assessments of behaviour for use in treatment studies.

Despite the recent developments in rating scales for behavioural measure in dementia there are still many methodological problems inherent in the use of such scales. The accuracy of behavioural ratings depends on the "validity" and "reliability" of the rating scale used. The "validity" of a rating scale refers to whether the scale measures the behaviour it is intended to measure. "Reliability" refers to whether two different raters, or the same raters on different occasions, will produce the same results. A scale may therefore be reliable but not valid for a particular behaviour or set of behaviours. However, if a scale is not reliable it can not be accurate and therefore valid. In order to ascertain the validity of a rating scale one needs to have an external measure of behaviour against which to compare it. This is often not available for subjective behavioural scales, except for comparing a new scale with existing scales. Usually the reason for producing a new scale is that the existing scales are deficient in some respect, thus this method has limitations. The reliability or consistency of a scale is easier to assess. Particular items may be compared over various conditions and this is how the accuracy of behavioural ratings are most frequently measured.

The accuracy of ratings depends on how often the rater is in contact with the subject. Items concerning night time behaviour have been found to have particularly low reliability. Patterson et al (1990) found that the Behave-AD item rating the amount of wakefulness at night was omitted by carers 20% of the time, usually because they had not observed the patient during this time.

Finkel, Lyons and Anderson (1992) examined the reliability and validity of the Cohen-Mansfield Agitation Inventory (CMAI) with 232 elderly patients residing in a large nursing home. They compared the ratings obtained on the CMAI with ratings from the Behave-AD and the Behavioral Syndromes Scale for Dementia (BSSD - Devanand et al, 1992) across three working shifts: day, evening and night. Correlations between the three scales were significant for the day and evening shifts but did not reach significance during the night shift. This suggests that rating behaviour during the night is problematic rather than a fault with the CMAI. Finkel et al (1992) also found that inter-rater reliability was good for items about physical aggression and verbal agitation but not for items pertaining to "physical non-aggression" (e.g. disrobing, hoarding, intentional falling), although these behaviours were infrequent and therefore difficult to observe accurately. Inter-rater reliability across shifts was only moderate, which may be because levels and types of agitation vary across shifts.

Ratings of behaviour by nurses or relatives can also be affected by the raters' perception of losses or gains associated with reporting behavioural problems. Caregivers may be keen to acquire extra assistance with caring for the dementia patient and hence over-report problems. Alternatively, relatives may worry that they will be seen as unable to cope if they report too many or too severe disturbances. It requires time and motivation to accurately fill in a behavioural rating scale and this may be an important consideration in the case of nurses' ratings, especially for busy ward staff.

The subjectivity of rating scales may be desirable for some items such as "irritability" where the rater must judge if the response to external stimuli is warranted or excessive. However, the subjectivity of the rater may introduce unnecessary error in

others, such as "frequency of pacing", for which a more objective method of measurement might be more appropriate.

Conclusion. Early rating scales in dementia were designed to measure multiple deficit domains. The cognitive component of such scales expanded and separated since it allows for the direct assessment of the subject. Factor analysis of rating scales can divide the remaining components into ability to perform daily activity (functional ability) and social or psychiatric-type behavioural change. Factor analyses from some of the purely behavioural studies and rating scales breaks down the behavioural groupings further into passive-type behaviours and agitated-type behaviours.

Although rating scales are the primary method of measuring behavioural disturbance in dementia, there are a number of methodological flaws associated with their use. The validity of behavioural rating scales is difficult to assess and the reliability of some items is poor, notably for behaviours which occur infrequently and night time disturbances. Ratings of behaviour are largely subjective and are open to the problems of bias, associated with the believed outcome of reporting behaviour problems.

6. Physical activity as a measure of behavioural change in dementia

The analysis of rating scale items, prevalence and treatment studies shows that certain types of overt, observable behaviour are commonly reported as behavioural problems in dementia. Most of the behaviours described can be said to fall into one of two groups: (a) behaviours lost or performed less frequently, and (b) behaviours that are new or excessive. Group (a) includes many depressive type symptoms such as

passivity, under-activity and non-communication. Group (b) includes such behaviours as wandering, agitation, aggression, sleep disturbance and repetitive stereotyped behaviours. Many of these excess behaviours appear to manifest a change in either patterns of activity or absolute activity levels. In other fields of behavioural research where disturbed behaviour has been identified as manifesting itself as increased activity levels, objective measures of physical behaviour have been used.

7. The measurement of physical activity

La Porte et al (1985) has identified more than 30 methods for measuring physical activity in humans. The 7 categories they identified are: calorimetry, physiological markers, job classification, dietary assessment, surveys, direct observation and mechanical and electronic measures.

Some of these methods are primarily concerned with the amount of energy expended during various activities. Such methods include dietary assessment and calorimetry, which involves the measurement of oxygen consumption through the analysis of expired air. Physiological markers used include the measurement of oxygen consumption directly, the examination the metabolism of doubly-labelled water and the monitoring of heart rate. The validity of heart-rate monitoring depends on the accurate definition of the relationship between heart rate and energy expenditure, which is complicated by a number of variables such as gender and exercise training (Acheson et al, 1980). These methods are somewhat invasive and would interfere with the assessment of behaviour in a natural setting.

Direct activity has been measured by survey method. Large surveys of work forces were conducted, whereby the workers kept diaries of the types of volitional activity engaged in. Williams et al (1989) claim of the three most *popular* methods of activity measurement, two involve self-report measures, namely, self-report diaries and interview or self-administered activity recalls (the other popular method is electronic motion sensors). Although self-report measures of activity can be accurate (Klegges et al, 1990), the diary method of activity measurement is clearly not appropriate with subjects who may not wish to, or are not able to faithfully report their activities such as behaviourally disturbed patients.

Behavioural observation techniques have their origins in ethology and anthropology and have been used extensively in developmental psychology. The ethologist methods for recording behaviour in animals can be particularly suitable for the assessment of non-verbal behaviour in humans. Observers are trained in the use of a coding system where by they can quickly and efficiently record samples of behaviour. However, observers may slowly reinterpret the meanings of the behaviours they are requested to observe during the course of assessment. This has been called observer "drift" (Reid, 1970) and continual retraining may be needed to avoid this. Complex behavioural codes may be needed to analyse complex behaviours. As the complexity of a code increases, its reliability may suffer, although insufficiently exact codes may leave room for observer bias in the assessment (Foster and Crone, 1980). Behavioural observation is most commonly used for short periods of time as it is very labour intensive. Rating scales have been developed for measuring neuroleptic-induced akathisia which involve scoring movements according to their frequency or duration, combined with a subjective rating of restlessness. Both these observational techniques do not allow for long term monitoring of behaviour and are unlikely to be of use for nocturnal assessment of behaviour.

Numerous mechanical and electronic methods for the measurement of activity have been developed. Activity has been measured in laboratories by the use of photoelectric cells placed on the side of a room, with a light source placed opposite. When light is obscured by the movement of a subject it causes a counter to be activated. A similar idea, but using ultrasound waves to detect motion has been used (Dabbs and Clower, 1973) but both these methods are constrained to one area and provide results that are difficult to generalise (Tryon, 1985).

An early method of mechanically measuring naturalistic activity was developed by Schulman and Reisman (1959). They had self-winding watches modified so that wrist movement would cause the minute hand to move on, with the hour hand and calendar date advancing in response to minute and hour hands respectively, as usual. Measurement of activity is achieved by taking note of the "time" and "date" on the watch before and after the experimental epoch, giving a figure for activity units over that time. These adapted watches, named "actometers", were used fairly extensively in the nineteen sixties and seventies, especially in the study of hyperactive children (Tryon, 1985). They have the disadvantage of only giving one measure of activity each time the actometer is examined.

"Pedometers" work by a system of gears that are moved by the displacement of a delicate balanced arm on the horizontal plane. Pedometers are usually used to measure distance travelled, walking or running, by the addition of a stride adjustment which can be preset for different size of stride. These monitors are a popular, inexpensive method for assessing home exercise routines, however, pedometers tend to underestimate low rates of activity and overestimate high levels of activity (Montoye and Taylor, 1984).

A type of counting device that measures the number of times movement is made to a different plane was developed by Stevens (1971) to measure rocking movements in mentally retarded subjects. The instrument is based upon a mercury ball which is free to move when rotated, thus opening and closing an electronic circuit. This is called "telemetry" and activity is recorded as the number of circuit closures. The degree of movement which makes the mercury ball move can not be adjusted once the device has been constructed, thus a monitor which accurately records large movements may not register small deviations from the plane.

More sophisticated measurements of activity can be obtained from the use of accelerometers. A piezo-electric crystal becomes deformed due to accelerative forces generated by movement, which causes a change in voltage. The number of times the voltage changes, in a given time sample, is counted and stored in a microprocessor chip. An advantage over the other counter methods is that the rate of acceleration which causes a change in signal can be pre-selected. Accelerometers have been shown to have excellent test-retest reliability on tests with subjects on a treadmill (Meijer et al, 1991). Wong et al (1984) found the commercially available "Caltrac" monitor had a "roughly linear increase" in accelerometer output with oxygen consumption in treadmill tests. The technology in the accelerometer has recently been miniaturised and thus makes a small, effective method for measuring human activity.

Sleep researchers have been quick to realise the advantages of using these eminently portable activity measuring devices. Aubert-Tulkens et al (1987) used a wrist worn activity monitor to measure therapeutic drug effects in patients with sleep apnea syndrome. They report the method to be valuable and effective for measuring sleep disruption and comment on the increased validity of results collected in the natural

environment (that is, at home in bed rather than in a sleep laboratory). Mullaney, Kripke and Messin (1980) found wrist worn accelerometers to be accurate in estimating sleep as compared to scoring electroencephalogram (EEG) recordings in hospital and non-hospital patients. Activity monitoring with accelerometers has been used to measure activity cycles in healthy normal subjects (Lieberman, Wurtman and Teicher, 1989) and activity changes associated with depression (Wolff, Putnam and Post 1985; Teicher et al, 1988). At the time of conception of this thesis there was no published account of the use of activity monitoring with dementia patients.

Conclusion. Physical activity has been measured through the assessment of energy expenditure, self-report measures and ratings, by direct observation and by mechanical and electronic methods. Electronic monitors have the advantages of not interfering with subjects' usual daily routines and behaviours. They allow continuous non-labour intensive monitoring and highly reliable and objective data acquisition and storage. The most technologically advanced of these electronic monitors are the accelerometers. These monitors can have adjustable sensitivity, for assessing different intensity behaviours and have been miniaturised for minimum inconvenience to subjects.

8. Research aims

In 1986 the Health Services Research Committee of the Chief Scientist for Scotland instigated a multi-disciplinary Working Party on the Care of the Dementing Elderly. The working party was given the remit to review the published research on factors affecting the care of the dementing elderly and identify important areas for new research with the emphasis on service requirements and not solely academic interests.

The 1987 Chief Scientist Organization report highlighted the importance of new research into the assessment and management of behavioural problems. After reviewing the literature on the pharmacological management of dementia they concluded "there was little uniformity in rating scales, and many were unsatisfactory". The Working Party identified research priorities including:

"The development of valid and reliable rating scales with which to rate the sort of disinhibited behaviour which may precipitate admission to hospital and make nursing care difficult in hospital." CSO (1987)

The above research was recommended as a precursor to the evaluation of drugs in the control of "disinhibited behaviour". However, the use of rating scales to measure disturbed behaviour has disadvantages, particularly in treatment studies, where the accurate assessment of potentially small changes in behaviour is important. This thesis examines a novel measure of disturbed behaviour in dementia which may overcome the problem of accurate measurement by providing quantitative data.

Solid-state activity monitoring is a relatively new method of measurement. Activity monitors were successfully used with normal adults, children and depressed patients but not with any subjects with such potentially disturbed behaviour as can be seen in dementia. La Porte et al (1985) cite four important criteria to aid the evaluation of methods of measuring activity. A new measure is required to be: (1) valid; (2) reliable; (3) practical - it must have acceptable costs to both investigator and subjects; (4) non-reactive - it must not alter the population or the behaviour it seeks to measure. The aim of this work is to evaluate the practicality, validity and reliability of the use of activity monitors as a measure of behavioural disturbance with dementia patients.

Preliminary work was carried out to examine the properties of different types of

accelerometer to find the one most suited for use with dementia patients. The study of feasibility began with establishing whether wearing an activity monitor was acceptable to some or all dementia sufferers. As discussed above, the behaviours of dementia patients change through out the course of dementia. The issue of acceptability depends on how the patient reacts to having a monitor placed on their wrist and this cannot be predicted in advance. This work attempted the use of activity monitors with a broad range of dementia sufferers, from very mild to very severe. Whether the monitors are acceptable to patients or not has implications for their reliability and validity as a measure with this population. If more disturbed patients refuse to wear a monitor, it cannot be a valid measure of disturbed behaviour; if patients constantly remove the monitor and put it back on again it may prove an unreliable measure.

The data provided by the activity monitor were examined by visual inspection of activity graphs, for face validity and consistency and by statistical analysis. Normative data was collected to assist with the decision about the best method of data analysis. The activity patterns of a large group of controls was examined and compared to the dementia sample. The validity of monitoring activity for the assessment of behavioural disturbance was examined by comparing ratings of behaviour to activity levels in a mixed severity group of dementia patients. This study also examined the association between degree of cognitive decline, behavioural ratings and activity levels. A final study looked at the effects of medication on agitation in severe dementia patients. This with-in patient design examined the possible degree of behavioural and activity change within individuals.

CHAPTER 2

Instrument Design and Selection.

1. Introduction

This chapter concerns the preliminary investigations into the feasibility of using electronic monitoring equipment with dementia patients. The first question to be addressed was whether patients would accept the attachment of an electronic monitoring device. It was necessary to ascertain whether dementia sufferers would be alarmed by such equipment, which would cause ethical problems, or whether they would keep a monitor on even if they did not find it intrinsically unpleasant. Several types and makes of activity monitors are available, with different methodological (e.g. counting mechanisms) and practical (e.g. size) characteristics. Different activity monitors were assessed for acceptability to patients and method of data collection likely to be most appropriate. Dr Jaques, a consultant psychogeriatrician who allowed access to his patients on two psychogeriatric wards, believed the problem of noisiness was an important aspect of agitation, which could possibly be measured objectively. A method of noise recording was attempted with dementia patients.

2. Voice recording

Behaviour problems which are manifested in a verbal form are commonly reported in patients with dementia. Cohen-Mansfield (1986) measured verbal behaviour problems in the form of "strange noises, screams", "cursing or verbal aggression"

and "constant unwarranted requests for attention / repetitive sentences". These were found in 14%, 66% and 64%, respectively, in her sample of 66 cognitively deteriorated elderly. Teri et al (1989) reported 11% out of their sample of 56 Alzheimer's disease sufferers, showed "verbal aggression to others" more than twice a week. Zimmer, Watson and Treat (1984) found "verbally disturbing to others (noisy, abusive etc.)" behaviour occurred in 12.6% of 1,139 patients in geriatric skilled nursing facilities. Gilleard and Watt (1982) found 27% of carers of a sample 65 dementia patients who attended a day hospital reported "noisy, shouting" to be a problem, and 15% reported "bad language".

Both the level of noise and content of speech can be aspects of problem behaviour. The level of noise made by a patient is a directly observable behaviour which can be measured by objective means. An ordinary tape recorder can record noise levels but this method is unsuitable where a number of sources of noise are found together, such as on a hospital ward. A voice monitor was designed by the Edinburgh University Department of medical physics for use in this study. The voice recorder consisted of a medilog tape recorder, worn around the waist on a belt, connected by a wire to a commercially available microphone attached to the neck. The microphone delivered sounds to the medilog recorder which then stored the vocal information in terms of loudness over time. Thus actual speech content was not recorded. Initially the microphone was attached to a band which was then placed around the neck of the patient.

Three dementia patients were identified by a consultant psychogeriatrician as being vocally disruptive but otherwise not agitated, and therefore, most likely to tolerate investigation. I attempted to use the noise monitoring system with these patients to

assess the usefulness of this approach. The neck band is not uncomfortable to wear (a subjective evaluation by researchers) but it was not tolerated for more than a few minutes by any of the dementia patients. Following this failure the design was modified by Mike Glabus. A diaphragm, about the size of a 10p was stuck directly to the throat, over the larynx, with double sided electrode tape. A tiny tube carried the sound vibrations to the microphone, now situated at the waist recorder. Although this was slightly more acceptable to four other patients, none tolerated the diaphragm for more than 17 minutes.

Neck Band		Throat Diaphragm	
Subject	minutes worn	Subject	minutes worn
1	6	1	12
2	<1	2	11
3	4	3	5
		4	17

Informal observations of patients during the voice recording trials revealed that noisiness, such as shouting, occurs in bouts between quiet phases hence this design of monitor cannot be of use in this situation. It is currently impractical to try and monitor the sound made by one patient from any distance from that patient due to the amount of background noise on a psychogeriatric ward. It was concluded that more development, possibly militarisation, is required before voice monitoring can have any application with ward dwelling dementia patients. Such development was considered to be beyond the scope of this work and voice monitoring was

subsequently abandoned.

3. Activity monitoring

The monitoring of human activity has undergone revolutionary advancement due to the use of new surface mount techniques for constructing microchips and the use of solid-state memory. This new technology has allowed the militarisation of monitors, most of which can now be worn on the wrist as a self-contained unit. Activity monitors basically consist of an activity-sensing transducer and an eraseable programmable read only memory (EPROM). Different types of activity monitor have been developed, such as pedometers, actometers and telemetric devices (described in chapter 1) but the accelerometer is the most flexible and easily miniaturised type of activity monitor available. All of the commercially available activity monitors work on the accelerometer principle.

As the name suggests, the transducer works by sensing acceleration. A piezo-electric crystal becomes deformed due to accelerative forces generated by movement, which causes a change in the voltage passing across the crystal. Movement occurs in three dimensions but most human activity shows up and can be measured on all three planes (Webster et al 1982, Redmond and Hegge 1985) thus it is only necessary to sense acceleration on one plane in a monitor. Redmond and Hegge (1982) found that the amount of acceleration generated by human activity usually falls in the range of 0.25-0.5 gs of force, with occasional bursts of up to 1g. This means it is possible to pick up most movements with one setting of accelerometer, set for a threshold of

0.1g. Some models of monitor are now available with adjustable sensitivity accelerometers, although we could not obtain one for our evaluation.

An activity monitor was initially obtained from Professor Swaab at the Netherlands Institute for Brain Research. Professor Swaab and colleagues developed an activity monitor which was used with a number of dementia patients to investigate disturbance in circadian rhythm. These patients were not particularly agitated although their sleep patterns were abnormal (subsequently reported by Witting et al, 1990). The monitor consists of an accelerometer mounted in a small plastic casing worn on the wrist. This is connected by wire to a microprocessor storage unit which is worn around the neck, like a large pendant. Data from the transducer is stored in microchips called EPROMs. A disadvantage of this monitor is that the storage unit has to be unscrewed after each use to recover the EPROMs.

In order to test this monitor it was placed on two mild to moderately demented patients living in the community (with in-house carers) and four severe dementia patients from long stay hospital wards. The community patients were well known, having participated in local Alzheimer's drug trials in the past. The dementia in-patients were selected by a consultant psychogeriatrician as being typically disruptive on the ward, with wandering or pacing as their main behaviour. Both of the two mild/moderate patients wore the monitor for two days and nights, although the carers commented that the wire connection was troublesome. Of the four severe dementia in-patients only one patient tolerated the monitor for three days and nights. Two patients removed the entire apparatus while the other ripped the wire from the wrist-worn transducer. The EPROMs collected from the three patients who tolerated a monitor were sent back to the Netherlands Institute for Brain Research for analysis.

Unfortunately they were apparently damaged in the post and no results were obtained.

Due to the low acceptability of the monitor and the problems with analysis in another country it was necessary to abandon this monitor also. At this time a number of activity monitors became available commercially. An evaluation of three brands of monitor was carried out in order to assess suitability for work with dementia patients. This evaluation was carried out in conjunction with Mr Mike Glabus of the University of Edinburgh Department of Medical Physics. Each of three manufacturers lent one of their activity monitors for evaluation. The individual parameters of the monitors are set out in table 3.1.

Table 3.1. Design type and cost (1989) of three commercially available activity monitors.

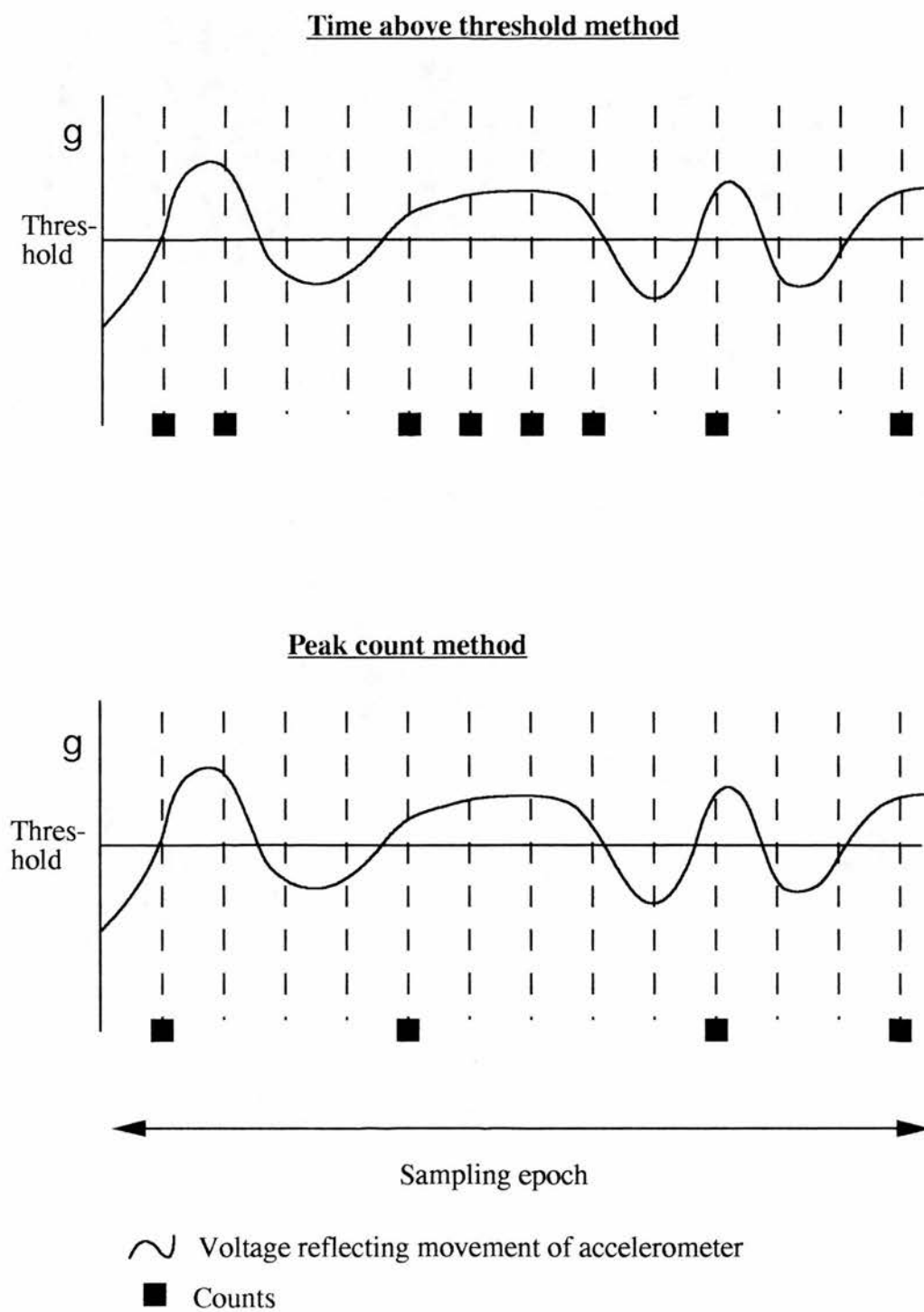
Monitor type	Transducer site	Cost per monitor	Sampling method	Sampling epoch
Minilog	Waist	£900	PCt	4-2048 secs.
Geahwiler Electronic	Limb / wrist	£700	TAT	0.375 - 3600 secs.
Actometer (Zak GmbH)	Limb / wrist	£1000	PCt	120 secs.

Abbreviations used: Time above Threshold (TAT); Peak Counting (PCt); seconds (secs).

In each type of activity monitor the continuous analogue signal from the accelerometer

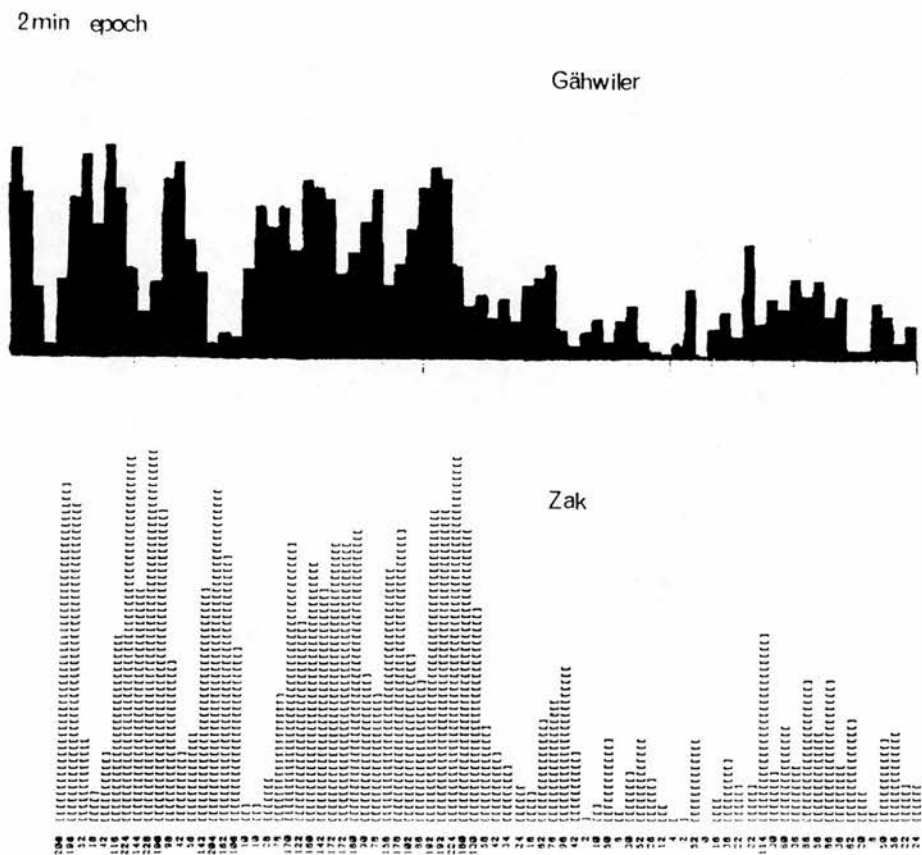
requires conversion to digital format for data storage in the memory. Two methods are employed by the manufacturers; either peak counting (PCt) or time-above threshold (TAT). Figure 3.2 shows how the two sampling methods work. Each monitor has a background sampling rate, which is indicated by the dashed vertical lines. The number of counts registered for each monitor type is shown by the black blocks. The peak counting method registers a count every time activity (represented by changes in voltage) goes over the threshold. It will not register another count until activity has dropped and risen again above the threshold. The time above threshold method registers counts for as long as the activity level is above the threshold. Of the three monitors evaluated two were of the PCt variety (Minilog and Actometer) and the other is TAT (Gaehwiler).

Figure 3.2. Time above threshold and peak count sampling methods compared.



It was necessary to determine if any major difference existed in results obtained by the PCt and TAT sampling methods. A number of volunteers in the University of Edinburgh Department of Medical Physics wore the Gaehwiler (TAT) monitor and the Zak (PCt) monitors on the same wrist site for a continuous 24 hour period. Figure 3.3 shows a typical pair of recordings. These plots show activity values for two minutes epochs, over only two and a half hours in order to show the detail of the recording. The two methods show almost identical recordings.

Figure 3.3. A comparison of activity recordings over 2.5 hours for a time above threshold monitor (Gaehwiler) and a peak counting monitor (Zak)



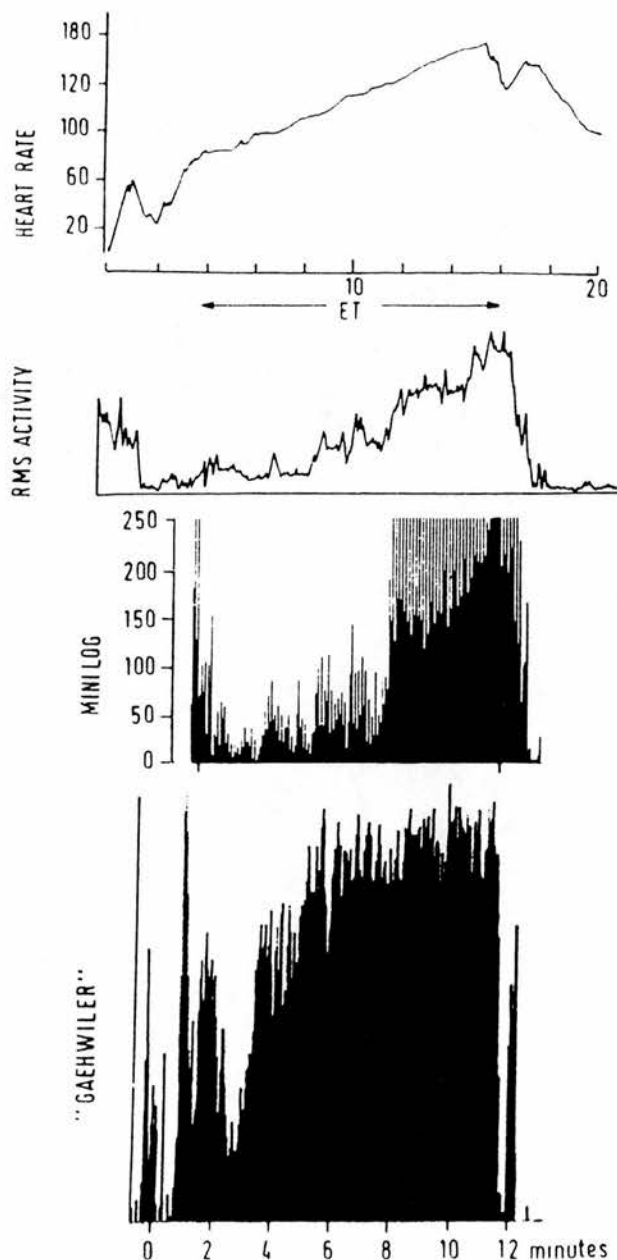
It is not practical to store these raw counts, generated by either method, as it would quickly use up large amounts of memory. Each monitor sums the number of counts over a known epoch, which may be fixed or adjustable depending on the monitor type. The Minilog and Gaehwiler monitors allow the epoch to be determined by the researcher. High frequency behaviours (e.g. running) set to a small sampling epoch may saturate the measurement by producing the maximum number of counts in successive epochs.

In order to make an independent evaluation of the activity monitor data outputs, in the assessment of the impact of wrist and waist location, it was necessary to develop a mechanism which recorded raw data signals. Mr Glabus built such an activity monitor using a medilog tape-recorder as the data storage component. The transducer consisted of a piezo-ceramic cartridge with an off-centre mass attached to it, which acted as an accelerometer. The monitor was attached to a belt which was worn around the waist of the subject. In the first instance I put this monitor on an extremely active wandering dementia patient for three half hour sessions. In order to examine the face validity of this raw signal I also made simultaneous recordings of the patients' behaviour with a video camera during this time. A running verbal description of the behaviour on the film was sufficiently close to the raw signal that it could be followed by a second observer from the commentary of the first. Such an activity monitor, of relatively bulky proportions situated at the waist, could not be used for night time monitoring, and may present problems with patients who do not normally wear belts (most female patients).

Mr Glabus (a normal healthy subject) wore the Minilog monitor on a waist belt, the Gaehwiler monitor on the right wrist with the raw signal recorder transducer on his

left wrist. He underwent a graded exercise test on an exercising machine in the Cardiology Department at the Royal Infirmary of Edinburgh. Four speeds were recorded over the 12 minute test which went from gentle walk up to jogging. The two commercial monitors' recordings are compared with heart rate and the raw signal in figure 3.4. The raw activity signal was transformed by electronic low pass filtering and full-wave-rectifying to produce an approximation to the root-mean-square (RMS) of the raw activity, which gives a smoother trace.

Figure 3.4. A comparison of heart rate, RMS activity, Minilog and Gaehwiler activity monitors over a twelve minute graded exercise test.



Both the Minilog and Gaehwiler activity monitors were set to sample 10 second epochs. The waist worn Minilog recorder reaches its ceiling after 6 minutes, where as the wrist worn Gaehwiler monitor does not saturate during this test. This was probably due to the sighting of the Gaehwiler monitor on the wrist. Both monitors to follow heart rate and RMS activity fairly well.

4. Conclusion

Some of the patients examined during pilot studies were observed in very active behaviours, including running. The Minilog monitor might show a ceiling effect with such active patients, making the detection of small changes in activity problematic. (However, it may be possible to circumvent this problem by adjusting the sampling epoch). Many severe dementia patients are non-ambulant but still show a significant degree of agitation. This may include moving legs or only upper body movements. The Gaehwiler monitor would be suitable for such patients and there is apparently no disadvantage to recording major body movements (including walking) from a wrist worn sensor (Webster and Hegge, 1985). Considering problems with earlier bulky instruments, it was clear that less obtrusive monitors were more likely to be acceptable to patients. The Gaehwiler monitor is the most compact and light monitor available and is significantly cheaper than most of the rival products. Thus because of (a) small size, (b) light weight, (c) cost, (d) worn on a wrist, it was decided that Gaehwiler activity monitors should be purchased for the study of activity in behaviourally disturbed dementia patients.

5. Practical considerations with the use of the Gaehwiler activity monitor

Five monitors were purchased for this research. The monitors are 5cm long by 3cm wide by 2cm high and weigh 64 grammes. The monitor is accessed by the computer interface using a small unscrewable port on the side of the monitor. Four tiny batteries power the monitor, which are accessible through a second port in the monitor. A new set of batteries will last for a year or more. A basic software package is provided. This allows the data to be read from the monitor to the computer, enables the user to adjust various parameters used by the monitor and gives basic data presentation.

The monitor must be set to operate in the first instance. Information about the date and time is taken from the computer and reset in the monitor with each use. A delay can be programmed into the monitor so that the start time may be a future date or time. A few initial attempts to set up a start delay caused errors in the system, so this delay facility was not used further. A careful note was taken of start and end times of subjects' wearing the monitor and data generated before and after these times was edited out later. Length of sampling epoch can be adjusted from 0.375-3600 seconds with a default time of 10 seconds. At this rate of sampling the monitor can record continuously for 4 days.

After the monitor has been removed from the subject it must be connected to the interface in order to read the data into the computer. The software available allows data to be entered into a number file which can be displayed on screen and edited if

necessary. A graphics program is available which prints out the data as a graph with 24 hours on each line (see appendix). This format gives an easily visual method of examining the data for individual cases. Patterns of day and night time activity are immediately obvious with ordinary subjects.

The number file generated by the interface cannot be read into other data processing programs hence it was necessary to write further software to access and manipulate the data. A program called ACT was developed by Mr Glabus. This program allows data to be grouped into varying epochs from one minute to as many hours as are available. The results of these grouping can be displayed numerically or histographically. For each chosen epoch the program places all the values present into one of thirteen categories, each category containing progressively higher value ranges than its predecessor. The histograms generated by this method are a useful method for initial visual analysis of activity levels during a certain epoch (at night time for example). The ACT program also generates a mean for each epoch. In order to read the "means of epochs" data directly into other processing packages it was necessary to convert the data to an ASC II format. The ACT program was modified by Dr John Starr of the University of Edinburgh Department of Psychiatry, to allow this output format .



CHAPTER 3

An Assessment of the Reliability and Validity of Activity Monitoring in Severe Dementia Hospital In-patients and its Relation to Nurse Ratings of Behaviour Problems.

1. Introduction

The pilot work described in chapter 2 determined the most suitable type of activity monitor and established that some patients with senile dementia could tolerate a such a wrist worn activity monitor. This chapter is concerned with establishing the level of reliability and validity of this method of measurement. The basic overview of the approach is as follows. Activity monitors were placed on a sample of severe dementia hospital in-patients, to assess their level of acceptability within this population. Patients' behaviour problems were rated by nurses on a novel rating scale which I developed for this study, in order to examine the validity of activity monitor results. The data were examined for distribution properties and diurnal rhythm.

1.1. Reliability

Three important questions need to be addressed to establish the reliability of these monitors: (1) mechanical robustness; (2) consistency of measurement and size of difference effects; (3) consistency of tolerance of monitors.

(1) mechanical robustness. Will the monitors break or cease to function when worn by dementia patients, with or without behaviour problems?

(2) consistency of measurement and size of difference effects. Is the counting mechanism consistent enough for comparing within patient and between patients activity levels? The reliability of the counting mechanism is guaranteed by the manufacturer to be the same for each monitor within a 10% error margin. For random use with large numbers of subjects this is probably satisfactory, although such an error may be too large for small numbers or single-case study within patient designs. To be able to judge an acceptable size of error it is necessary to have some knowledge of the size of difference expected both within subjects and within samples. Initial work was required to sample a range of behaviours and subjects to provide this baseline information. This was assessed by visual inspection of the activity graphs for internal consistency within subjects and for range of difference between the most active and least active patients. (This will also give a measure of face validity of activity graphs).

(3) Consistency of tolerance of monitors. Will the monitors be removed so frequently by patients as to affect the reliability of the measure? Record sheets were kept by nurses to monitor if or how often activity monitors were removed by patients.

1.2. Validity

In order to show activity monitors to be a valid measure of behaviour disturbance in dementia patients the monitors are required to fulfil several the criteria: (1) acceptability to subjects; (2) measurement of the full range of activity; (3) face validity as a measure of activity levels; (4) the distinction of problem behaviour from other behaviour.

(1) Acceptability to subjects. The most important criterion to establish is the acceptability of wearing an activity monitor. The validity of an activity monitor as a

method of measuring behaviour disturbance rests on the assumption that the monitor will be tolerated by the subjects wearing them. This is especially important in patients with extreme behavioural problems.

(2) Measurement of the full range of activity. Redmond and Hegge (1982) found that the amount of acceleration generated by human activity usually falls in the range of 0.25-0.5 gs of force, with occasional bursts of up to 1g. This means that it is possible to pick up most movements with one setting of accelerometer, set for a threshold of 0.1g. The length of sampling epoch is adjustable with the Gaehwiler monitor; it has a default rate of saving one "total of counts" value every 10 seconds (as discussed in chapter 2). Pilot work with the Gaehwiler monitor found that no ceiling effect was generated by adult jogging, at this sampling rate, therefore the monitor is adequate to measure most normal human activity. However, if high frequency behaviours occur and the monitor is set to a small sampling epoch, it may saturate the measurement by producing the maximum number of counts in numerous successive epochs. The default rate of 10 seconds per epoch was used and activity graphs were inspected to ensure no ceiling effects were present. The study described in this section determined the suitability of this method for recording the particular behaviours of dementia patients.

(3) Face validity as a measure of activity levels. The graphs of the least and most active patients will be examined for easy differentiation.

(4) The distinction of problem behaviour from other behaviour. This work addresses the question of whether the monitor can differentiate between behaviours said to be normal and those said to be disturbed. The evaluation of disturbance is made by nursing staff who have the greatest contact with these patients. A rating scale is developed which contains items of observable behaviour which are

likely to reflect differences in activity levels when the behaviours are present or absent. Cluster analysis is performed on the data to examine whether activity levels distinguish sub-groups of over-active or under-active patients.

Hypotheses :

- (1) Activity monitors will withstand the physical rigours of use with dementia patients.
- (2) Activity monitors will be tolerated by patients with severe dementia and not frequently removed
- (3) Visual inspection of activity graphs will show data to be consistent over three days and the range of data between the least and most active subjects will be so substantial as to allow these patients to be distinguished by visual reference to their activity graphs. No ceiling effects will be visible in activity graphs.
- (4) The monitor results will allow the distinction of patients with certain types of behaviour problem from those who did not exhibit the problem, as rated by nursing staff.

2. Method

2.1. The sample

Patients for this study were selected from eight typical long stay psychogeriatric wards (approximately 180 patients). Four were in the Jardine Clinic at the Royal Edinburgh Hospital and four at the Royal Victoria Hospital, both in Edinburgh. The nursing notes of all patients in these wards were examined for suitability in the study. Initially notes were checked for the diagnosis of dementia, either Alzheimer type or

multi-infarct dementia, made previously by the consultant. The full medical records of such cases were checked to ensure the DSM-III-R criteria were met for primary degenerative dementia (dementia of the Alzheimer type) or multi-infarct dementia, which includes the exclusion of patients with histories of high alcohol consumption, traumatic brain injury, psychosis or depression. Some of the medical records were deficient in some aspects of information required, but a policy of exclusion by the presence of contra-indication was followed. Thus subjects could not all be rigorously diagnosed as suffering from either Alzheimer's disease or multi-infarct dementia, but there was no evidence to suggest their symptoms were caused by other medical or psychiatric conditions. This was to ensure a sample of patients with typical presentations of either of the two commonest dementias. All patients met the DSM-III-R criteria for severe dementia in that their "activities of daily living are so impaired that continual supervision is required, e.g. unable to maintain minimal personal hygiene; largely incoherent or mute."

A majority of the patients on these wards had some concomitant medical complaint which may or may not have affected their activity levels. In some cases where mobility was poor (such as patients who did not walk) it was not clear if this was a result of brain degeneration, other pathology or motivation. A significant number of patients on these wards did not walk unaided. The site of the activity monitor on the wrist means that agitated upper body or arm movements are picked up, therefore it was decided that patients should not be excluded because of their inability to walk. The judgement of whether the patient suffered from an illness other than dementia which clearly affected their movement was made by medical staff (see below). This included patients with debilitating diseases such as severe arthritis and Parkinson's disease, both at the tremor and rigidity stages.

Many of the patients on the eight wards received some kind of medication for agitation

or restlessness. It was considered good medical practice by the consultants of the patients in this study to seek to reduce agitation, therefore very few patients with behavioural problems were medication free. Medications for this purpose show some, but limited usefulness (Schneider, Pollock and Lyness, 1990) therefore behaviour problems may be present in patients receiving drugs. Patients who received such medication were not excluded, in order to ensure that the subject sample was not biased to the less behaviourally disturbed. Furthermore, the medication used to treat behavioural problems can induce extrapyramidal side-effects (Jeste and Watt, 1982). These side-effects include involuntary movements such as shaking, which can be as severe as the agitation the drug is supposed to treat. Such "drug induced Parkinsonism" indicates a poor prognosis for the patient (Wilson and MacLennan, 1989). Patients may also suffer from the side-effect akathisia, which induces a feeling of restlessness or "not being able to sit still".

A list was made of patients fulfilling these criteria and this list was examined by either the ward consultant or the ward charge nurse. Further patients were excluded if the charge nurse or consultant deemed them unsuitable on medical or social grounds or if their next of kin were considered unapproachable.

2.2. Ethics and consent

Ethics approval for this study was obtained from the Lothian Health Board Psychiatry and Clinical Psychology Ethics of Medical Research Sub-Committee. The major ethical consideration is whether placing activity monitors on dementia subjects is an invasion of privacy. Patients suffering from severe dementia are unable to fully comprehend the details of research and are unable to give informed consent. It is usual in dementia research to approach the next of kin to give assent on behalf of the patient. However, patients can show consent by whether they co-operate with the

study. A patient may remove an activity monitor because they find it cumbersome or uncomfortable, or they may remove it for no apparent reason (fidgeting is common in dementia sufferers). Nurses were asked to replace a monitor if they found a patient had removed it. If it was removed numerous times, or patients displayed distress at the presence of the monitor, this was taken as a lack of consent and the monitor was permanently removed.

The next of kin of all patients who met the criteria and were deemed suitable were sent a letter of explanation about the study. Relative and patient information sheets were provided. These were written in consultation with consultant psychogeriatricians and were approved by the ethics committee. A consent form was included and those agreeing to allow their relative to take part in the study were required to return the signed consent form to me. To improve compliance an addressed envelope was included for this purpose. The letter of explanation was written in conjunction with the consultant for each ward and relatives were invited to refer to hospital staff with enquiries. Each ward was provided with sample letters and information sheets about the study.

Letters were sent to the relatives of 62 patients. One patient had no next of kin and permission was given by the consultant. 30 relatives replied giving permission. Three patients' health declined seriously between gaining permission and their projected entry into the study. Thus 28 patients were finally included in the study.

2.3. Instruments

The degree of dementia of each patient was assessed by examination with Folstein, Folstein and McHugh's (1975) Mini-Mental State Examination (MMSE). The MMSE is an extensively used and validated method for assessing dementia (Anthony et al,

1982, Folstein et al, 1985). It measures orientation attention and concentration, short-term memory, calculation, the ability to name, write a sentence, follow verbal and written commands and copy a diagram. A total score of 30 may be gained if all items are answered correctly. None of the twenty-seven patients were able to score any marks on the test, indicating severe dementia in all cases.

Ratings were obtained from the nursing staff pertaining to patient behaviour. At the time of investigation only one rating scale existed which was designed and validated exclusively for behavioural problems in dementia subjects. Reisberg et al's (1987) scale, the behavioral pathology in Alzheimer's disease rating scale (BEHAVE-AD) measures 7 areas of behaviour : delusions, hallucinations, activity disturbance, aggression, diurnal rhythm disturbance, affective disturbance and anxieties and phobias, with 25 items. This scale contains many items which are unlikely to be related to activity changes, namely delusions, hallucinations, anxieties and phobias. To use this scale in full would place an unnecessary extra time burden on the nursing staff. Therefore it was necessary for me to construct a new, brief scale for use in this study.

The criteria for the new behaviour rating scale were as follows. The number of items needed to be low in order to encourage maximum co-operation from nursing staff. This was especially important since all patients were sought from only four wards and each patient would require two raters. Initial contact with nurses found them to be friendly but not able to devote more than a few minutes daily, to this research. The items chosen reflected behaviours most likely to be measurable by activity and noise monitors. (This scale was developed before the noise monitor was dropped from study).

Six items were chosen which were thus described in the scale.

1. Noisiness - rate how much noise / speech the patient makes which is louder than necessary or is felt to be excessive in quantity.
2. Irritability - rate how irritable/ hostile or aggressive the patient is with staff and other patients.
3. Agitation - rate the extent to which the patient indulges in repetitive purposeless behaviour (except wandering).
4. Wandering - rate how much the patient wanders or paces without any apparent goal or purpose.
5. Withdrawal - rate the extent to which the patient lacks social responsiveness and interest in their environment.
6. Sleep disturbance - rate how often the patient gets up or causes some disturbance during the night.

An attempt was made to quantify and provide operational definitions. Four possible categories were included.

0- Behaviour usually not present.

1- Behaviour infrequent / occurs on occasion but does not require special management. 2- Behaviour fairly frequent / occurs sufficiently often for staff to adopt a specific approach or tactic when dealing with the patient.

3- Behaviour very frequent / warrants a serious attempt at reducing behaviour through specialist intervention or treatment (e.g. drugs, physical restraint, behaviour modification).

See appendix I for a copy of the "Dementia Activity Rating Scale"

2.4. Procedure

The activity monitor was placed on each subject for at least 74 hours. During this

time the monitor was only removed by nursing staff if the patient was bathed or showered. A record sheet was provided for each patient wearing the monitor. Nurses were asked to record either staff removal of the activity monitor for more than thirty minutes. Staff were not asked to record short removals of the monitor in an effort to prevent disruption to usual ward routine. Staff were also requested to report if the monitor was found removed from the patient and asked to estimate, if possible how long the monitor had been removed. From the time of removal, it is possible to determine how long the monitor has remained unmoved, although it is not possible to tell who last moved the monitor. The activity monitors come in two colours and to avoid confusion no more than two different coloured monitors were present on one ward at the same time. Each record sheet bore the name of the patient, the colour of monitor and the times when recording began and ended.

3. Results

3.1. Acceptability of activity monitoring

Twenty-two of the twenty-eight dementia patients tolerated the monitor for the full 72 hours. Of the patients who tolerated the monitor 17 were women and 5 men. There mean age was 83.4, ranging from 79 to 88. Of the five unsuccessful attempts three monitors were found to have the delicate accelerometer broken inside the monitor and the three other monitors were (persistently) removed by the patients. Two were subsequently found on the ward, the other was permanently lost. The broken monitors were repaired by the manufacturer under warrantee. The monitor record sheets showed that the monitor had not been removed regularly by most subjects or carers for more than half an hour at a time

3.2. Graphic representation of the data

The stored activity monitor data from each subject are printed out as a graph, using software supplied with the monitor. These plots show daily activity over the three days, plotted from 12 noon each day through to 12 noon the following day, on each line. Visual inspection of these graphs for individual patients provides a guide to approximate amounts of activity over time. Most subjects' activity profiles showed a small amount of activity whilst a small number showed large amounts. The most and least active plots (patients AB and BD) are shown in figures 3.2.1 and 3.2.2 respectively. These two graphs can be easily distinguished from each other and reflect the descriptions of the patients' behaviour. The plots for all subjects are consistent over the three days.

AB

The patient who produced the graph in figure 3.2.1, had suffered from dementia for 8 years at the time of recording and was 84 years of age. AB was mute except for rare nonsensical utterances and was not able to perform any of the usual tasks required for daily living, such as feeding herself. She suffered from no other major medical complaint other than dementia, although she was frail and could not get up or walk unaided. AB's behaviour was restricted to sitting in a chair displaying very agitated rubbing movements with her hands, occasionally lifting a leg in the air or rocking forwards in the chair in an attempt to rise. AB remained awake for most of the day, taking only occasional naps and slept well most nights. She received 1mg haloperidol daily for agitation.

BD

The graph in figure 3.2.2 was produced by patient who had suffered from dementia for 10 years and was 81 years old. She was largely mute, incontinent and unable to

stand or walk unaided. She spent her day seated in a chair on the ward. She sat quietly, unaffected by her environment, displaying little movement and napping regularly for short intervals.

Figure 3.2.1. 72 hours activity recording for patient "AB".

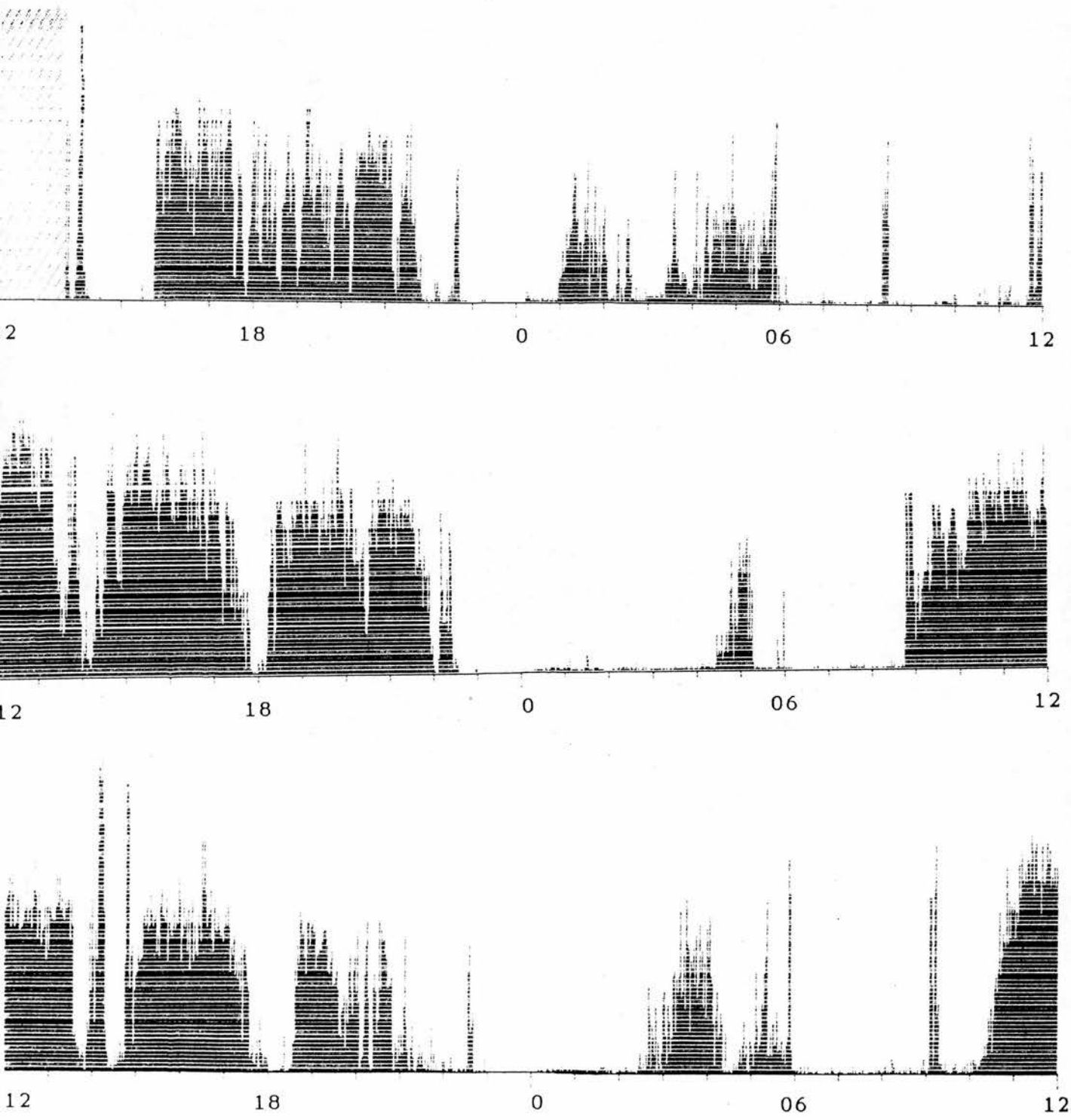
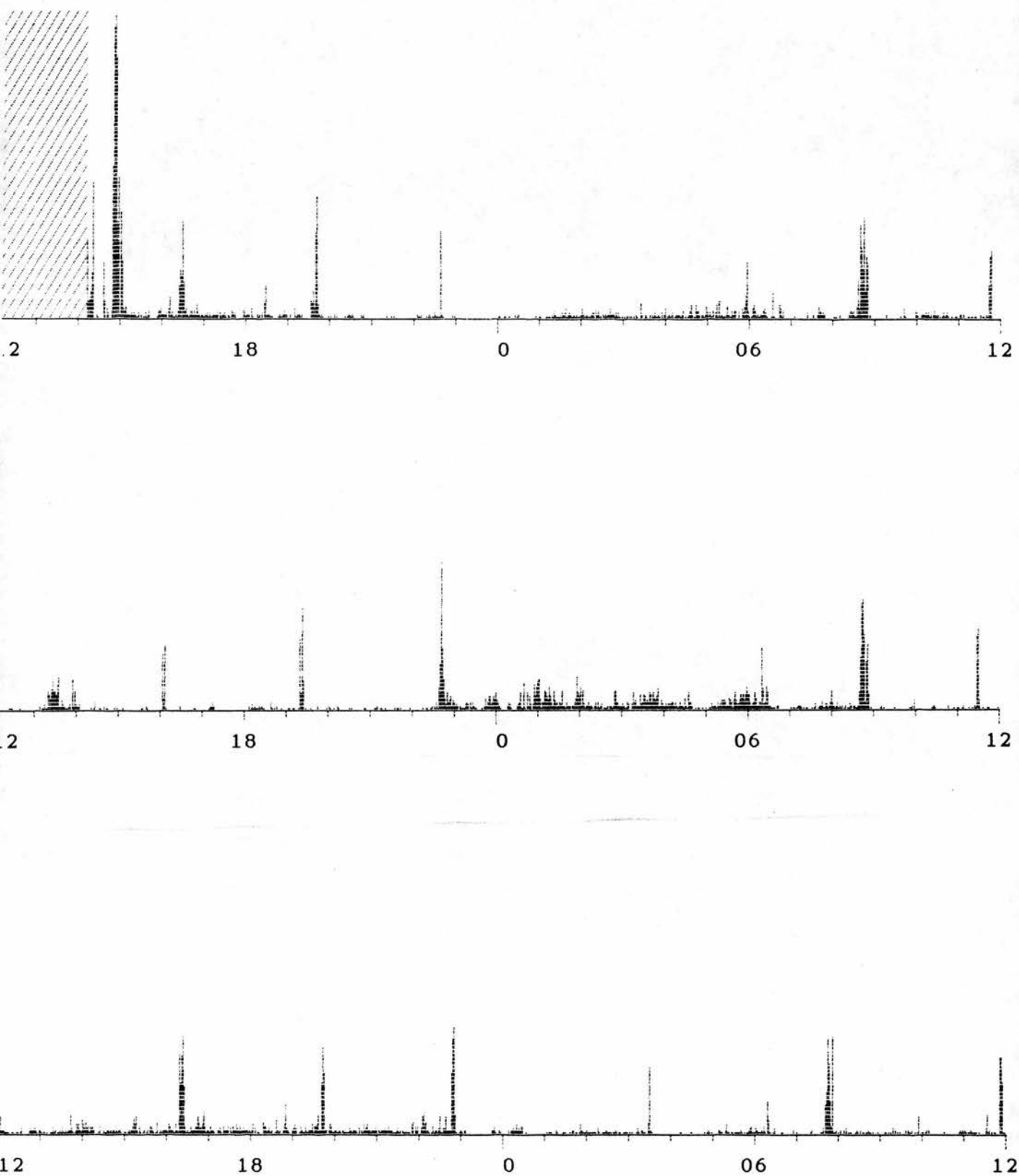


Figure 3.2.2. 72 hours activity recording for patient "BD".

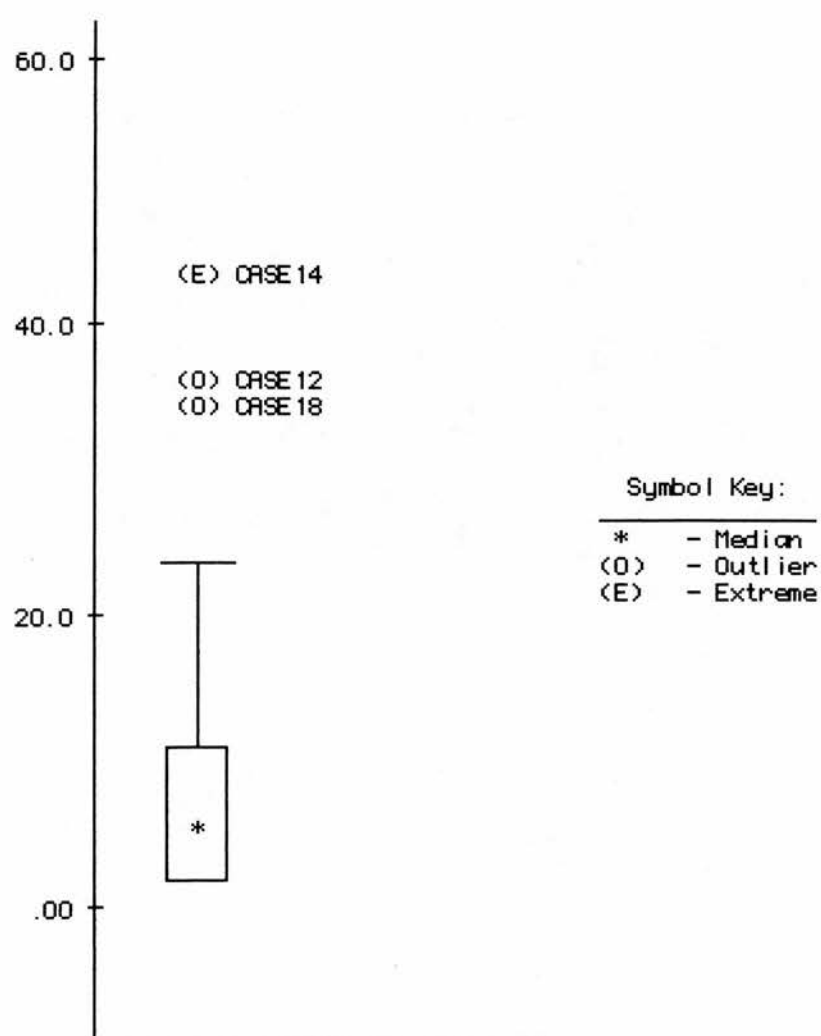


Data were converted into ASCII format giving an activity value for each of 72 hours for each subject. These data were then converted into a Macintosh file and entered into SPSS format for further analysis.

3.3. Distribution of the data

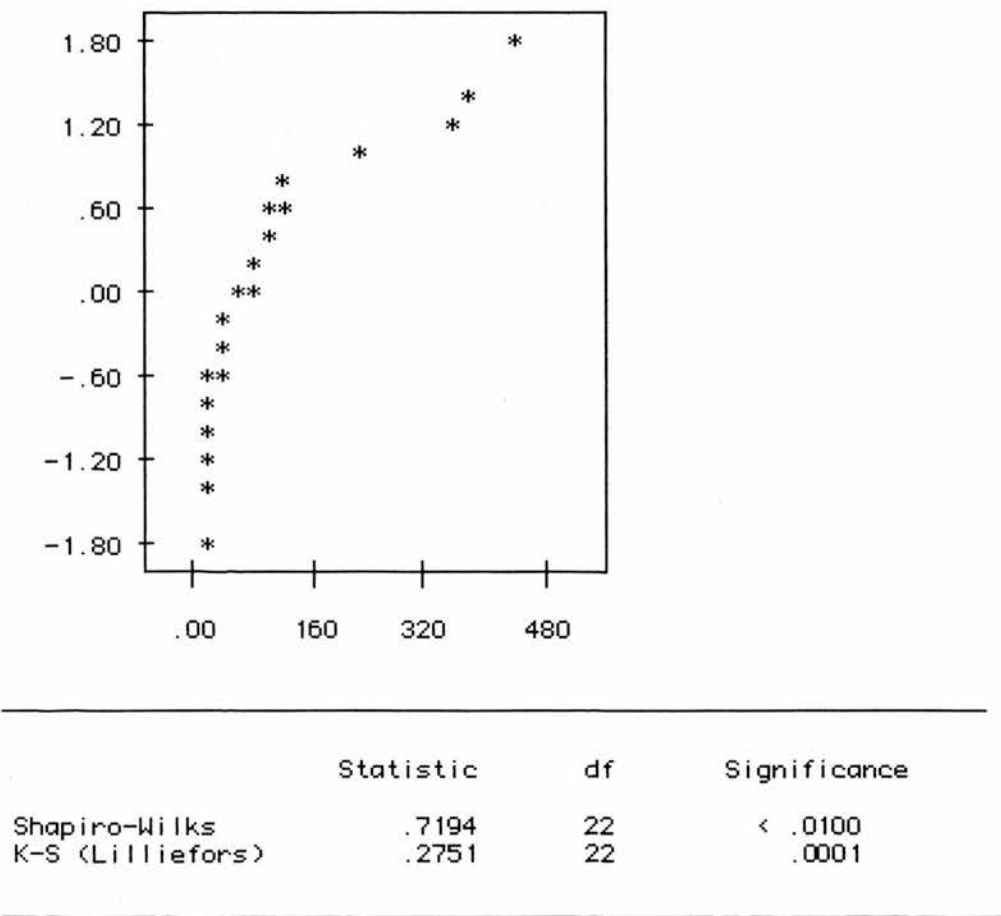
For each subject the data were averaged over the three days to give 24 hourly data points per subject. Box plots were plotted for each of the 24 hours. The plot shows the median, the 25th and 75th percentiles in a box and the upper bars of the lowest and highest observed values that are not outliers. Outliers, which are between 1.5 and 3 box-lengths from the edge of the box, are labelled "O" and extreme values which are more than 3 box-lengths from the edge of the box are labelled "E". The data are quite spread out with a number of extreme and outlying values. In most cases the median is towards the bottom of the box, showing a positive skew in the data (little or no measurable activity is most frequent). The sum activity of subjects over the three days and nights is plotted in figure 3.3.1 showing a similar positive skew.

Figure 3.3.1. Box plot of summed three days activity data.



A normal probability plot examines how closely the data fit normal distribution by pairing each observed value with its expected value form a normal distribution (based on the number of cases and their rank order in the sample). The normal probability plot for the summed activity data is shown in figure 3.3.2 A normal distribution in the sample would generate a diagonal straight line, hence these data do not appear to come from a normally distributed sample. SPSS computes two alternative statistics to test the hypothesis that the data come from a normal population, Lilliefors test (a modification of the Kolmogorov-Smirnov test) and the Shapiro-Wilks test. The significance values for the two tests are 0.0001 and 0.0100 respectively demonstrating a large difference between observed and the expected values for a normal distribution. The summed 72 hours activity data do not show a normal distribution.

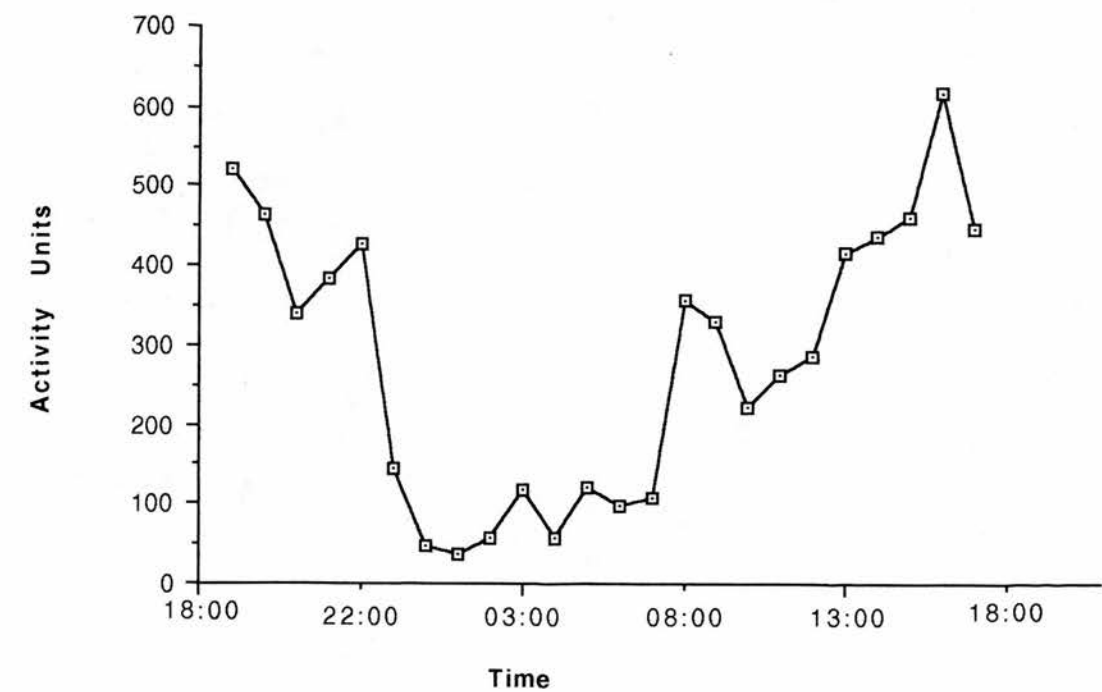
Figure 3.3.2 The normal probability plot for the summed three days activity data.



3.4. Diurnal rhythm.

The presence of extreme (large value) outliers results in unrepresentatively high mean values, and the strong positive skew in the data show that trimmed means or M-estimator values would also be inappropriate, hence the median provides the best estimation of group values. The data for each patient for each hour were summed from the 72 hours to give 24 hourly data values for each patient. The data displayed in figure 3.4.1 show the median values for the sample over 24 hours.

Figure 3.4.1. Diurnal activity rhythm, from median values of severe dementia patients.



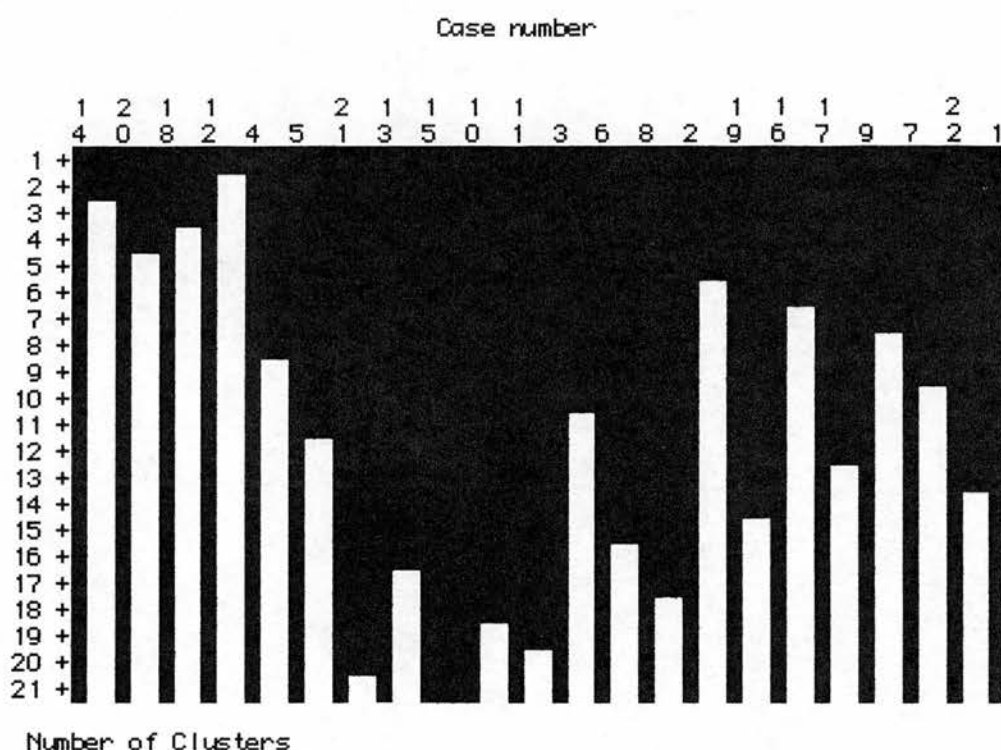
The pattern produced by the medians plot showed a clear drop over the night time hours, with activity increasing slowly until late afternoon.

The data were divided into epochs for separate analysis of different times of day, based on the results from control data, reported in chapter 4. The period of rest or "night" was taken to be 4 hours from 0200 until 0600, when none of the controls were consistently active. Other epochs were chosen to reflect the likely periods between meal times and sleep. The morning epoch: 0800 until 1200, the afternoon epoch: 1400 until 1800 and the evening: 1800 and 2200. Box plots and normal probability plots of each of these epochs show distributions similar to that of the summed data.

3.5. Cluster analysis

The skewed distribution of activity counts might indicate a sub-population of patients with high activity values. Inspection of the individual graphs supports this hypothesis. An agglomerative hierarchical cluster analysis was run on the data, with the variables of morning, afternoon, evening and night entered together. This method of clustering calculates the squared Euclidian distances of each variable for each case from all other variables. Initially it assumes the same number of clusters as cases (22 in this sample), then it pairs up the two cases with the smallest distances. With each successive step it pairs up another case, either with the first two cases (cluster one) or a separate case, whichever is closer. The results of this analysis are displayed in the vertical icicle plot in figure 3.5.1. The vertical axis shows the number of clusters and the horizontal axis labels each case number in the clusters. The analysis begins at the bottom of the plot with 21 clusters; 20 individuals make up 20 clusters and cases 15 and 10 are joined to make a second cluster. At the next stage up, cases 21 and 13 make one cluster, 15 and 10 the second and the other 18 are individual case clusters. This process continues until there is only one cluster containing all cases.

Figure 3.5.1. Verticle icicle plot showing hierarchical cluster analysis for the variables morning, afternoon, evening and night.



The most parsimonious grouping of this sample appears to occur when only two clusters are present, one cluster containing 4 cases (14, 20, 18 and 12) the other containing the remaining 18 (cluster II). A second SPSS procedure is available for calculating clusters. The procedure "quick cluster" requires instructions on the preferred number of clusters and calculates which cases should fall into these clusters from squared Euclidian distances. This procedure displays the pattern of values for night, morning and afternoon in each cluster. When "quick cluster" is run for 2 clusters it also puts 4 cases into cluster I and 18 cases into cluster II. Cluster I has high activity values across the 3 epochs, while cluster II has low activity across epochs. The mean values for the clusters are reported in table 3.5.2.

Table 3.5.2. Table of mean values of clusters I and II for the epochs of morning, afternoon, evening and night (rounded to the nearest thousand units).

Cluster	Night	Afternoon	Morning	Evening
I	39000	109000	88000	112000
II	4000	18000	14000	16000

Further back in the hierarchical clustering procedure it can be seen that the four cases from cluster I come together only in the final stages, suggesting heterogeneous patterning between different epochs. Cluster II is somewhat more stable reflecting the more common tendency for low activity across day and night. Hierarchical cluster analysis of the separate epochs does not produce any more homogeneous clusters. Vertical icicle plots for each of the four epochs alone are plotted in figures 3.5.3 to 3.5.6.

Figure 3.5.3. Verticle icicle plots showing heirarchical cluster analysis for night time.

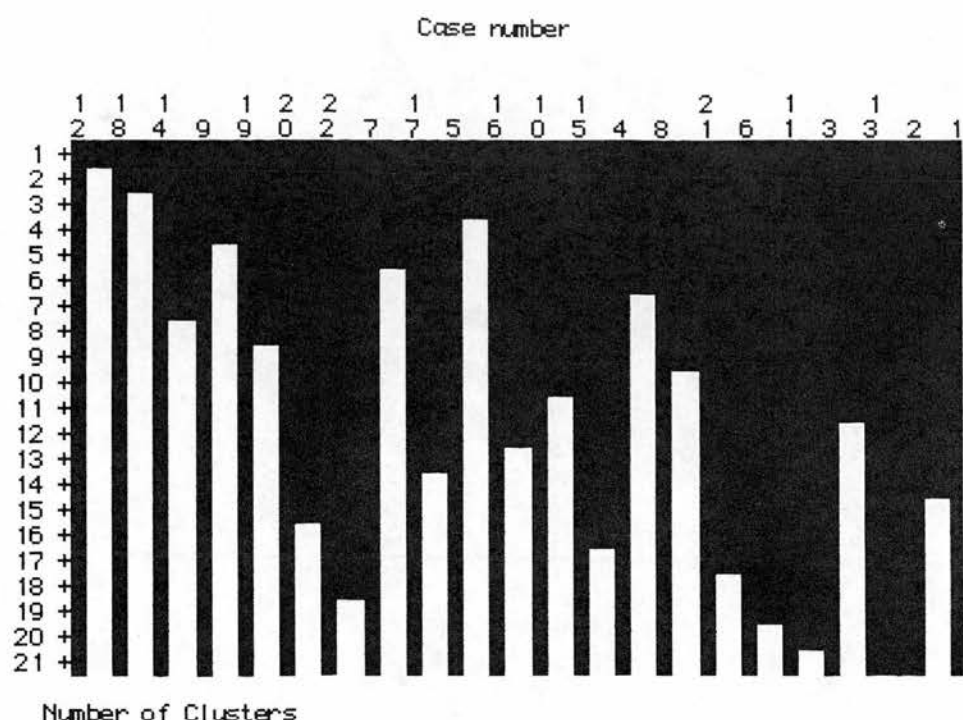


Figure 3.5.4. Verticle icicle plots showing heirarchical cluster analysis for the afternoon epoch.

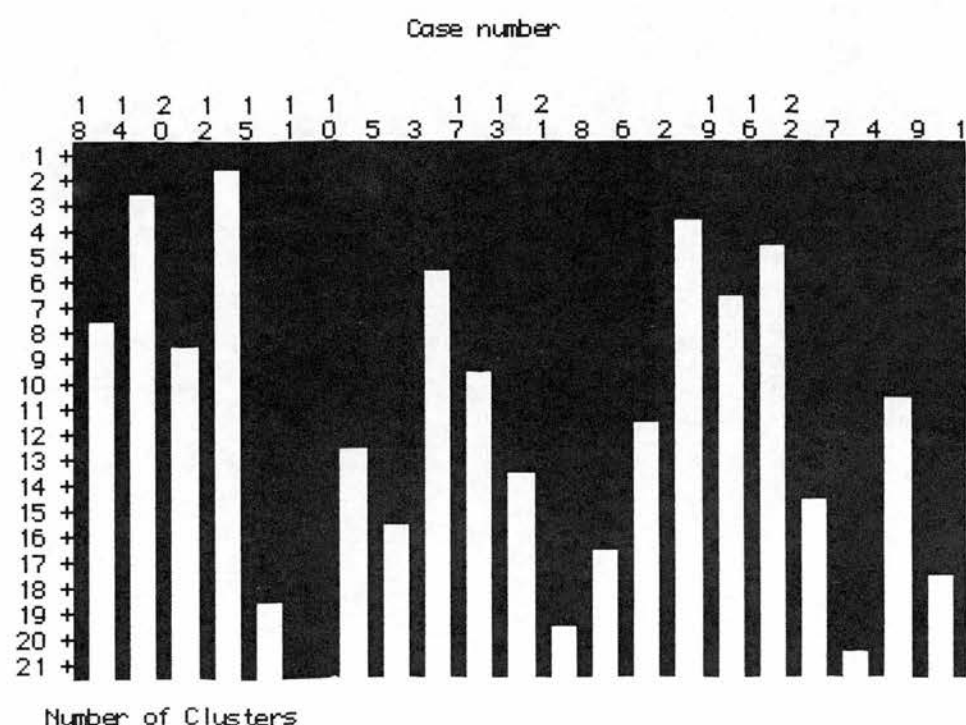


Figure 3.5.5. Ventricle icicle plots showing heirarchical cluster analysis for the morning epoch.

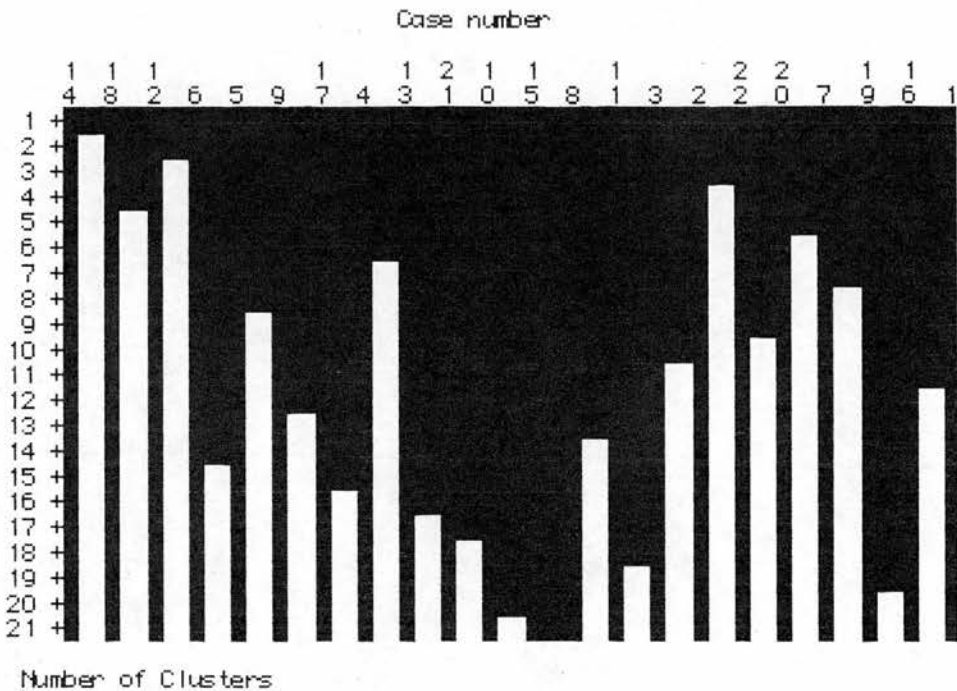
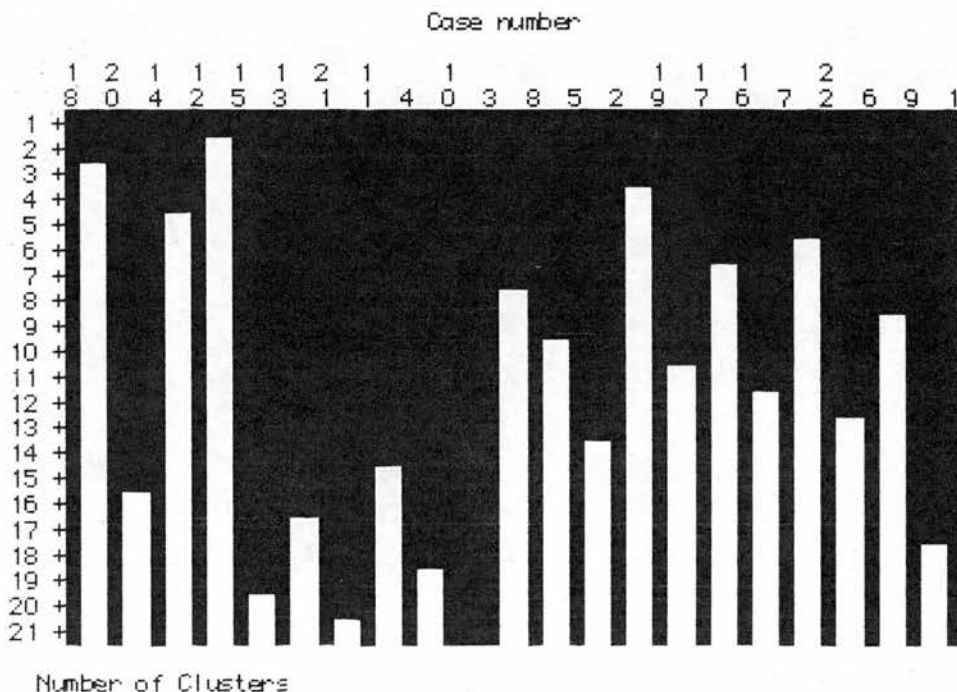


Figure 3.5.6. Ventricle icicle plots showing heirarchical cluster analysis for the evening epoch.



3.6. Dementia Activity Rating Scale Results

The inter-rater reliability of each of the five questions on the newly constructed scale were assessed. Cohen's (1960) kappa statistic is widely used in the assessment of reliability in rating scales. Landis and Koch (1977) proposed the following guidelines for the interpretation of kappa values:

- 0.00 to 0.20 slight agreement;
- 0.21 to 0.40 fair agreement;
- 0.41 to 0.60 moderate agreement;
- 0.61 to 0.80 substantial agreement;
- 0.81 to 1.00 almost perfect agreement.

The kappa statistic was computed between the two ratings for each item on the scale. See table 3.6.1.

Table 3.6.1. Kappa values for items on the dementia activity rating scale.

Item	Kappa value
Noisiness	.368
Irritability	.445
Agitation	.328
Wandering	.647
Withdrawn	.140
Sleep disturbed	.337

The only item with a value that displays "substantial agreement" is that of wandering. Where a disagreement arose between two raters the scores were averaged and these were converted to a 1-7 point scale (scores 0 and 0 =1, 0 and 1 =2, etc).to allow for any half marks generated by the mean. One-tailed Spearman's rank correlation

coefficients were computed between wandering and the four epochs: morning, afternoon, evening and night. See table 3.6.2.

Table 3.6.2. Spearman's correlation coefficients between wandering score and activity variables, morning, afternoon, evening and night.

Morning	Afternoon	Evening	Night	Sex
.100	.140	.397	.117	.034
(P=.330)	(P=.267)	(P=.034)	(P=.302)	(P=.440)

The only significant coefficient was generated between the wandering score and the amount of evening activity at the $P<0.05$ level.

4. Discussion

4.1. Reliability

(1) **Mechanical robustness.** Three monitors were found to be broken when removed from a subject. Nursing staff did not observe any patients' behaviour which they thought could result in a breakage (e.g. throwing it across a room). These monitors were repaired under guarantee. However it took approximately two months between sending a monitor for repair and receiving it back, which reduced the number of monitors available for experimental work. Gaehwiler Electronic claim to have made the accelerometer arm more robust and less susceptible to breakage and no monitor needed to be repaired a second time. Therefore Gaehwiler activity monitors

are sufficient robust for use in this type of study. The loss of one monitor on the ward was unfortunate because it transpired the monitors were not insured for loss away from the university department. This situation was immediately remedied, but the lost monitor was not replaced.

(2) Consistency of measurement and size of difference effects. Visual inspection of activity graphs showed similar levels and patterns of activity over the three days for most patients. The most and least active patients had clearly distinguishable activity graphs. The difference between these patients is sufficiently large that a potential 10% error in mechanical consistency would not be a significant influence on visual interpretation of the data. A within patient design using these monitors could rely on visual analysis with this error margin. This error would probably be unimportant between patients in a larger group study. Thus activity monitors provide a consistent measurement and show clear differences between patients.

(3) consistency of tolerance of monitors. The monitors were worn consistently by 22 of the 28 patients. Record sheets kept by nursing staff showed that monitors were usually not removed for over half an hour, even for washing, and therefore no record of removal was made. These severely affected dementia sufferers appeared to not notice or be concerned by the presence of an activity monitor on their wrist. Hence the monitors were tolerated consistently

4.2. Validity

(1) Acceptability to subjects. As stated above the activity monitor was well tolerated by most subjects. 3 of the 28 patients repeatedly removed the monitor and one patient was found to have removed the monitor to an unknown location. The

patients who removed the monitors were not the most behaviourally disturbed and could not be differentiated on grounds of cognitive deficit. It is not known whether the patients with the broken monitors had abused the machine on purpose, because they were not dexterous enough to take it off, for example, or whether they had been broken by accident. A monitor dropped from above waist height to a hard floor may have been broken. With a success rate of 80%, activity monitors are acceptable for use with this type of sample.

(2) Measurement of the full range of activity and (3) face validity as a measure of activity levels. The graphs of activity showed no ceiling effects with any of the patients, even the most behaviourally disturbed. Many of the patients showed very little activity, as represented on the graphs, but the activity monitors are sufficiently sensitive that this reflects a genuine state of inactivity. The graphs taken from the most active and least active patients allow clear distinction between the two patients from their clinical descriptions. The graphic representation of the data was made available to interested care staff, who made testament to its face validity.

(4) The distinction of problem behaviour from other behaviour. This investigation was made problematic by the poor inter-rater reliability of the behaviour scale. Although an attempt was made to increase the reliability of nurse ratings by defining the behaviours and categories of severity on the dementia activity rating scale, the reliability coefficients - kappa values, obtained for all items except wandering were too low to make use of the data collected. This may be because the definitions of behaviour were ambiguous or that the nurses were not sufficiently motivated to rate the patients carefully. Nurses were left with a rating sheet to complete in their own time, as this was felt by staff to be more convenient. The raters required a number of follow-up visits before all the requested ratings could be obtained. Possibly asking questions verbally for each case and the author recording

the results may have lead to greater consistency between raters.

The activity values for the sample are higher later on in the day and in the evening (see below). There is a significant correlation between evening activity values and nurses ratings of wandering, suggesting that the nurses assessment of behaviour is best reflected by activity monitor results when the behaviour is at its most extreme. A useful follow-up to this finding would be to examine nurses ratings of wandering at different times of day, to see if a generalised rating is an average of daily behaviour or a ratings of how a patient behaves at the worse time of day.

4.3 Distribution and diurnal rhythm

The distribution of the data showed a strong positive skew for all epochs, reflecting the tendency for low activity values in most subjects. This means that activity values must be treated as ranked data only. This unfortunately looses the large differences in activity values that some of the more agitated subjects show, compared to the median values. The cluster analyses do not support the hypothesis that a distinct sub-group of high activity patients exist. Hierarchical cluster analysis works by the synthetic approach of identifying the two most similar cases to form the first cluster, and it continues until all cases fall into one cluster. The question of deciding when to stop such an analysis is often made when the investigator believes the solution to be "clinically meaningful", for lack of an effective significance test (Kendell 1975). For a sub-population hypothesis to be supported with this small number of patients it would be required to be immediately obvious on visual inspection of the icicle plot. The analyses run on the activity data do not show distinct groups of patients, but provide further information on the distribution and distance of cases from each other. The main finding from these analyses is that the patients with higher activity values show less homogeneous activity patterns than those with low activity. There is a

continuum from the least active to the most active, although the spread of subjects becomes more sparse as values increase.

The medians of activity values give the best estimate of what is "average" for this sample. These plotted for each hour and displayed over 24 hours provide a graph of diurnal variation. The graph shows a clear drop in activity during the hours of night and an increase in activity over the course of the day to peak in the evening.

The term "sundowning" appears frequently in geriatric nursing manuals although there is little recognition or investigation of the syndrome in research articles (Loewenstein et al, 1982). This syndrome is usually reported to involve the exacerbation of disorientation, anxiety and agitation in dementia sufferers in the late afternoon or evening (Evans, 1989). Cohen-Mansfield et al.(1989b) conducted a detailed behavioural mapping of the behaviour and environment of eight dementia patients over a period of two months. Although they found increased agitation in two patients in the afternoon / evening, four others showed consistently greater agitation in the morning. The authors concluded that the type and frequency of behaviour varied greatly between subjects and that the temporal patterns of behaviour did not vary predictably across patients. Rindlisbacher and Hopkins (1992) placed telemetric-type activity monitors on two groups of six dementia patients, for 4 days each. One group were identified as "sundowners" by nurses, the others as "non-sundowners". Out of 24 patient days monitored for each group, increased activity in the afternoon / evening was seen in 12 days in both groups. Thus the "sundowning" effect was observed in half of all the days monitored, but this did not distinguish the two groups as rated by nurses.

The trend for the median activity plot to show a rise as the day goes on could reflect the so called "sundowning syndrome". However, the existence of this pattern of

behaviour as an important variable in dementia, has been questioned by most of the research into the phenomenon (Evans, 1987; Cohen-Mansfield et al, 1989b; Rindlisbacher and Hopkins, 1992). The rise in activity may reflect a trend also present in a healthy population, or the rise in activity may be so small as to be insignificant.

5. Conclusion

The activity monitors are well tolerated by most of the subjects in a sample of severe dementia hospital in-patients. The activity graphs generated make adequate visual representation of a range of behavioural activities in different patients. Nurse ratings of wandering correlated significantly with patients' activity values in the evening. Further work is required to establish if ratings of any other types of behaviour will correlate with activity monitor results. The data generated with this sample show a strong positive skew, with low activity values most common but with a number of very active patients. The pattern of activity values over 24 hours shows an increase towards early evening. This pattern needs to be compared to healthy elderly controls to establish whether the size of effect is significant.

CHAPTER 4

Activity Levels in the Healthy Aged. A Study of the Effects of Ageing on the Activity of the Very Elderly, and the Comparison of Activity Between Dementia Sufferers and Controls.

1. Introduction

Although the study of activity and behaviour in dementia sufferers is of interest in its own right, the patterns of activity observed might be more readily understood in the context of the behaviour of a sample of healthy elderly subjects. Normative activity monitor data would thus provide a base from which to build appropriate models for statistical analysis of the data.

The fitting of cosine waves to data displaying rhythms is called cosinor analysis. Cosinor analysis has been performed on a variety of biological data to detect circadian rhythms. The measurement of activity through sleep wake cycles is a convenient method for the detection of circadian rhythm changes which are altered in a variety of psychiatric conditions. Teicher et al (1988) successfully applied cosinor analysis to telemetric data collected from depressed elderly subjects. Brown et al (1990) and Leiberman, Wurtman and Teicher (1989) applied cosinor analysis to accelerometer data collected from young and elderly healthy controls. However, Witting et al (1990) found that cosinor analysis was inappropriate for the analysis of activity data, collected from their locally constructed accelerometer. The cosinor technique is assessed for suitability with Gaehwiler accelerometer data by application to control data.

The data from the healthy controls will be compared to that from the severe dementia

in-patient sample, investigated in chapter 3. The method of comparison will be decided from the control data analysis.

The severe dementia sample is a very elderly population, with a mean age of 83. It is possible that the low activity generally found partially reflects frailty due to advanced old age. Popular opinion is that activity decreases with the aging process. Physical activity is indubitably linked to health. High activity is associated with fewer cases of coronary heart disease, hypertension, obesity and non-insulin dependent diabetes mellitus. (Harris et al, 1989). Physical activity is also associated with better mental health. It reduces physiological stress and state anxiety and helps improve self-esteem. (Bridle and Fox, 1989).

The controls in the sample are all very healthy, but aged. Is the popularly perceived decrease in activity with ageing genuinely caused by ageing or is a reflection of a decline in health? This was investigated by comparing the activity levels of two samples of healthy elderly subjects, in groups aged 70-72 and 80-84.

Hypotheses:

- (1) The activity levels in the over 79 age group will be lower than those in the over 69 age group.
- (2) The control subjects will show greater activity levels than the severe dementia in-patients.

2. Method

2.1. The sample

Healthy elderly control subjects were initially sought through advertisement in three General Practices. Subsequently advertisements were placed in 10 sheltered housing or flats for the elderly. Very few suitable subjects were found through this method. Two subjects who wore the monitor were later excluded on grounds of age (92 years) and remained in productive employment.

A previous dementia study had arranged access to the case notes of elderly people in number of General Practices around Edinburgh. Four General Practices agreed to allow me access to case notes to find healthy elderly people who might act as control subjects. Due to the large number of case notes vetted, subjects were only selected if they were very healthy. Any with major illness or complaints, such as arthritis were excluded. Long standing successful treatment of stable hypertension was allowable as were non-serious digestive complaints, due their common occurrence in the elderly and lack of effect on activity levels. Those with diseases or injuries which might conceivably affect mobility were excluded. Lists of possible candidates were compiled and passed on to the patients' GPs for approval. The GP then looked over the case notes of the patient in question and decided whether that patient was suitable to approach on medical and social grounds.

2.2. Procedure

Letters describing the study were sent out to 97 people aged between 70 and 85 years, clustering around the low 70s and low 80s ages. A stamped addressed envelope was included for reply, upon receipt of which appointments were made to visit the house

of the subject with an activity monitor. The subjects wore the monitor for 74 hours, after which it was collected.

Subjects' cognitive status was assessed with the Mini-Mental State Exam (MMSE). The MMSE is a short test of 30 items which measures memory, orientation, verbal and spatial ability. The MMSE is described fully in Chapter 5. Subjects' activity data was only included if their score on the MMSE was 29 or 30. This high scoring level was selected to ensure no very mild dementia patients were selected, although it almost certainly biased the population to well educated, intelligent subjects. Since wearing the monitor was described in the introductory letter, it was felt polite to allow all interested subjects to wear the monitor, even if they had to be later excluded on the grounds of a low MMSE score. A short letter of explanation and thanks plus a copy of the activity graph, were sent to all participating subjects (this was offered as incentive in the introductory letter).

3. Results

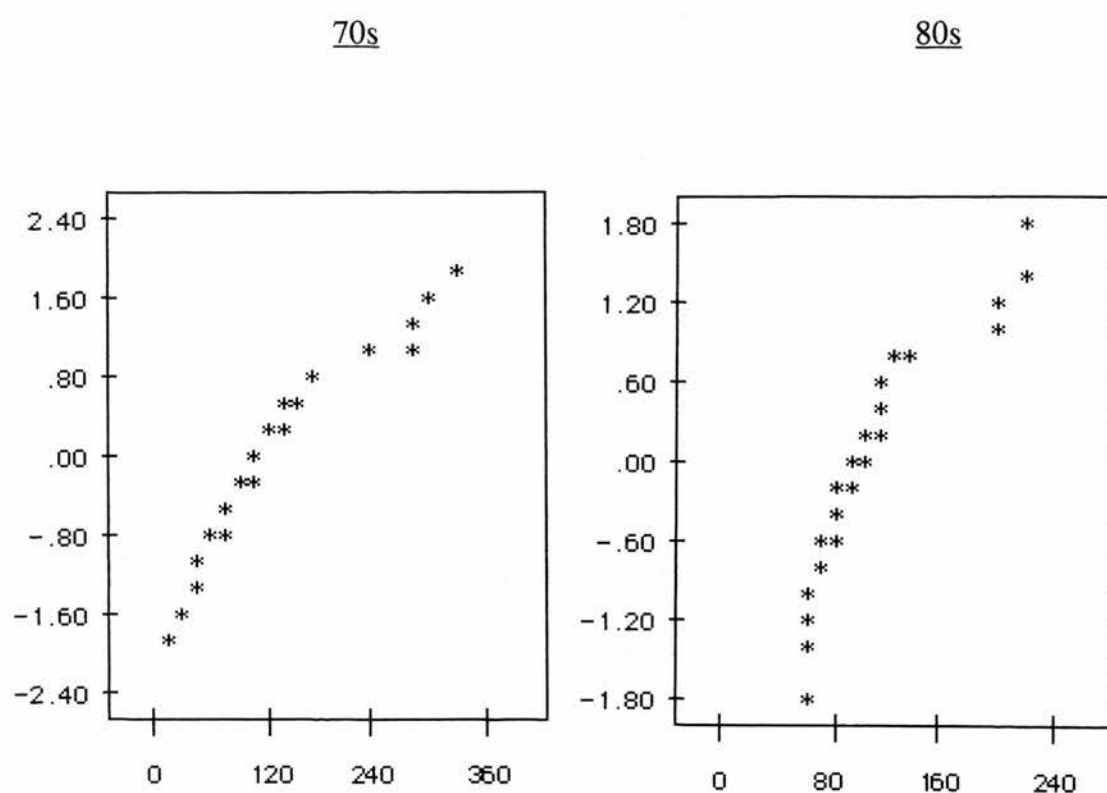
3.1. Examination of the Control Data

In total, 64 people replied to the letters of invitation to the study. Four subjects were excluded from the study due to a MMSE score below 29. One subject developed an allergic skin reaction to the monitor band and had to discontinue wearing the monitor (it was cleaned between wearers with soap, which may have caused the reaction). One subject became ill just before they were visited and decided not to participate. 58 subjects successfully wore the monitor and obtained MMSE scores of 29 or 30.

There were 33 subjects in the younger age group of 70-72 year olds (mean age 71.4) and there were 25 subjects in the older age group of 80-84 year olds (mean age 82.2). Two examples of typical controls are shown in appendix IV.

The data from controls were treated as the data for the dementia patients, described in chapter 3. The distribution of the control groups activity data shows positively skewed distributions, similar to the distribution shown by the severe dementia patients. Normal probability plots for the total activity data sets for both control groups are plotted in figure 3.1.1.

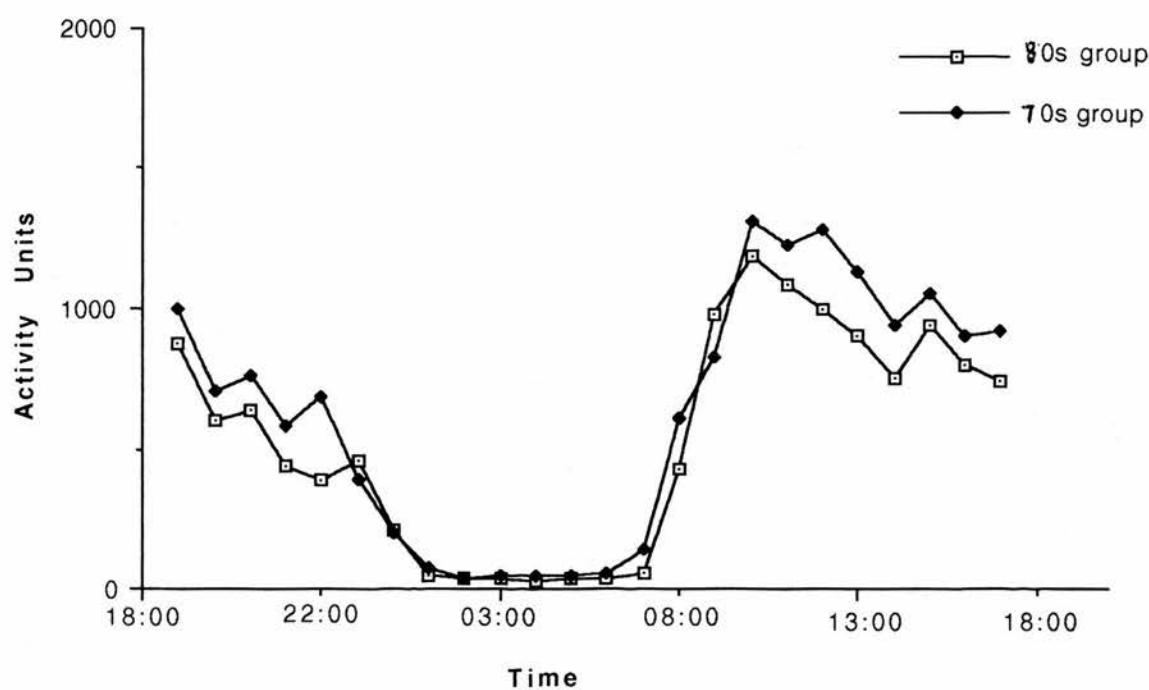
Figure 3.1.1. Normal probability plots of the summed total activity data for the 70s and 80s control groups.



(70s group)	Statistic	df	Significance
Shapiro-Wilks	.8876	33	< .0100
K-S (Lilliefors)	.1470	33	.0681
(80s group)	Statistic	df	Significance
Shapiro-Wilks	.8421	25	< .0100
K-S (Lilliefors)	.2008	25	.0106

The data for each patient for each hour was summed from the 72 hours to give 24 hourly data values for each patient. The median values for each of the 24 hourly values are plotted for the 70s and 80s groups in figure 3.1.2.

Figure 3.1.2. Diurnal activity patterns, plotted from 24 hours median values, for the 70s and 80s control groups.



As can be seen from the graph, the patterns of activity are almost identical. The 70s group appear to have very small but consistent higher activity values than the 80s group. The data from the 58 controls was examined to establish several epochs over the 24 hours, in order to be able to compare activity between groups, using statistical procedures. All controls showed a marked drop in activity in the evening which persisted until the next morning, when they can be assumed to be sleeping, or at rest in bed. The period of rest or "night" was taken to be 4 hours from 0200 until 0600, when none of the controls were consistently active. Other epochs were chosen to reflect the likely periods between meal times and sleep. The morning epoch is 0800 until 1200, the afternoon epoch is from 1400 until 1800 and the evening between 1800 and 2200.

The hourly totals from these epochs were summed to give one total activity value for each epoch, for each control subject. Non-parametric tests for differences in ranking order (Mann-Whitney U tests) were performed between the two groups for each epoch. The results are summarised in table 3.1.3.

Table 3.1.3. Mann-Whitney U tests for differences between the 70s and the 80s age groups for activity variables morning, afternoon, evening, night and total activity.

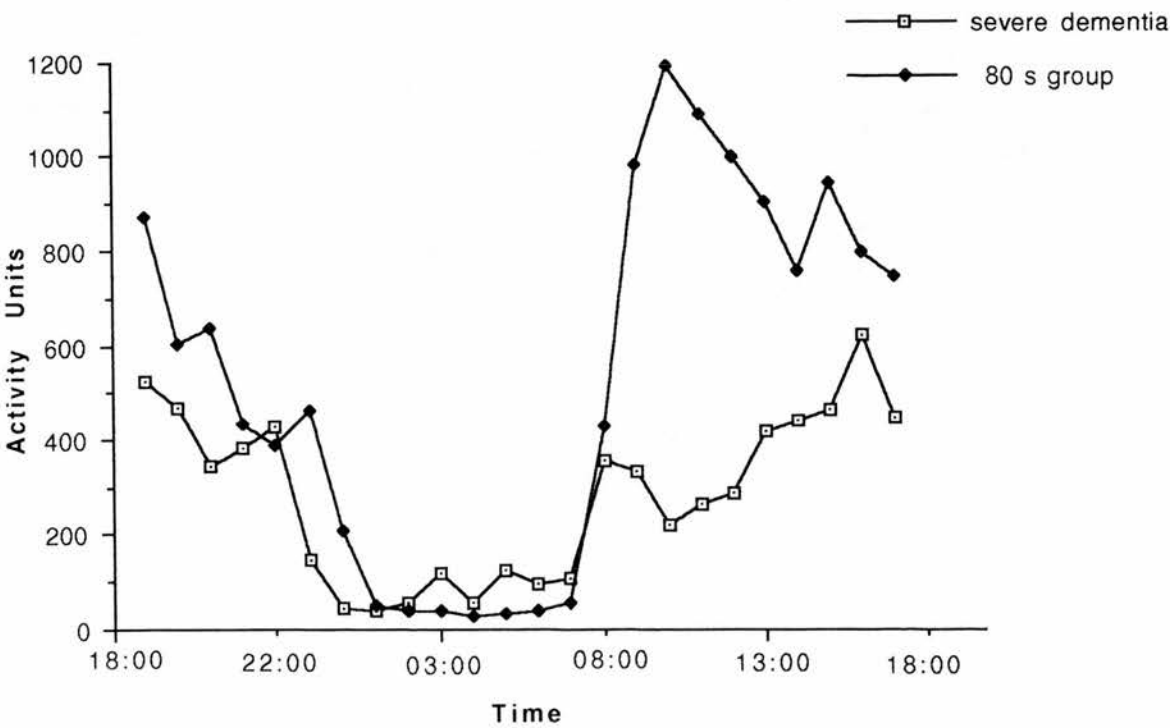
Variable	Mean Rank 70s	Mean Rank 80s	U	P value.
Morning	30.2	28.6	389	.712
Afternoon	30.2	28.5	388	.701
Evening	30.9	27.6	365	.456
Night	32.0	26.2	330	.195
Total Activity	31.0	27.5	363	.437

Table 3.1.3. shows there are no significant differences between the 70s group and the 80s group for morning, afternoon, evening, night or total activity.

3.2. Comparisons of activity levels between controls and dementia patients

The hourly median activity values were plotted for the 80s control group and the severe dementia patients in figure 3.2.1. The 80s control group (25 subjects, mean age 82.2) most closely resembles the dementia group (22 subjects, mean age 83.4) for numbers and mean ages.

Figure 3.2.1. Diurnal activity patterns, plotted from 24 hours median values, for the 80s control group and the severe dementia in-patient group.



As predicted, the severe patients group shows considerably less activity than the control groups. The drop in activity from morning through the day, observed in the control groups does not appear in the dementia sample. The dementia group demonstrated slightly increased activity levels until the early evening when they drop again. Mann-Whitney U tests were conducted to test whether the observed differences in activity were significant, by each epoch and for total activity. See table 3.2.2.

Table 3.2.2. Mann-Whitney U tests of rank differences between the 80s control group and the severe dementia in-patient sample, for activity variables morning, afternoon, evening, night and total activity.

Variable	Mean Rank Dementia	Mean Rank 80s	U	P value.
Morning	17.1	30.1	122	.001
Afternoon	19.1	28.4	166	.020
Evening	22.4	25.4	240	.456
Night	28.0	20.5	188	.064
Total Activity	19.6	27.9	177	.037

Table 3.2.2. shows that the reduction in activity values between the dementia sample and 80s control group are most significant in the morning (at the 1% level). The difference is smaller in the afternoon, but still significant at the 5% level. The evening activity values show no differences and the night time activity values are larger than the control groups, but the difference is not significant at the 5% level.

3.3. Cosinor analysis

The decrease of day time activity of many dementia patients and the increased night activity shown by some may be detectable by analysis of cosinor patterns in the data. A computer run cosinor program was obtained from Dr David Minors, Department of Physiological sciences, University of Manchester. The program was specially set up to receive activity monitor data in 6 minute totals, so that there were 10 activity values per hour. The program is constrained, that is it expects a period of one cycle per 24 hours, and cannot sensibly be used to detect different periods (personal communication with Dr Minors). The program fits a cosine wave to the data, describes the wave and gives a percentage of the data accounted for by the model.

Five controls from the 70s group and five controls from the 80s group were chosen randomly from within their populations. Their data was put through the cosinor program. The mean percentage of data accounted for by the cosine model was 17%, with a maximum of 25.11% and a minimum of 11.85%. These figures are very low and suggest the cosinor model is not an appropriate method of analysis for this data.

4. Discussion

4.1. Control data analysis

The measure of activity by electronic accelerometer is highly acceptable to controls. None of the subjects found the monitor sufficiently inconvenient that they wished to remove it. A number of subjects did comment that they would not have liked to wear the monitor for more than three days, but it is possible they would have made similar observations after two days if that was the length of time they had been requested to wear it. This method of measuring activity involves no time commitment on behalf of

the patient and hence is likely to be preferable method of measuring activity to time consuming diary keeping

The activity patterns of the 70s and 80s groups were virtually identical. Although the 80s group showed small but consistently lower values for most of the day time hours, these differences were not significant when the data were compared by epochs. This result suggests that if there is any truth in the belief that people become less active as they age, it is probably due to declining health rather than a property intrinsic to ageing itself. This comparison was conducted between a small range of years (only 10) so it may be that changes in activity occur over a much longer period.

The results from this study are in keeping with those of Witting et al (1990) who studied human activity using accelerometers. They found no differences in day time activity between 6 young (range 29-55 years) and 12 elderly (range 71-85 years) subjects. Leiberman, Wurtman and Teicher (1989) also used accelerometers to compare activity in a group of 40 older subjects (mean age 73) with activity in a younger group (mean age 26.1). They found the elderly subjects were " somewhat more active" than the young subjects, especially in the morning. The peak activity of the elderly subjects occurred at around 1.30pm, about 2 hours before the peak activity for the younger subjects.

The cosinor analysis program proved not to be an appropriate method of analysis for these data. With only approximately 20% of the data being accounted for with the cosine model, differences between individuals would need to be very large before they assumed significant levels. A larger number of cycles of data put into the cosinor analysis improves the accuracy of the fit (Leiberman, Wurtman and Teicher, 1989). It is possible that an increase in the number of days of data collection would have produced data suitable for this method of analysis. The decision to monitor

individuals for only three days was taken early on in this work after remarks from a number of individuals suggested that any longer may have become a nuisance. It was assumed that compliance from dementia subjects would be a major problem hence the number of days of monitoring was kept to a minimum. Three days was judged enough to allow estimates of the consistency of behaviour.

Witting et al (1990) also found that only a small proportion of their accelerometer data from controls and dementia subjects was accounted for by the cosinor method. They also point out that an hour-by-hour analysis would be overly complicated by enforced social factors. The "evening" epoch is likely to reflect such factors, and not be particularly meaningful in comparisons between controls and dementia patients, because it reflects bedtimes. The epoch of "night" was chosen deliberately late at night (2.00am) to avoid differences in activity caused by varying bedtimes.

4.2. Dementia patients compared to controls.

The activity patterns of the dementia patients and the 80s control group look quite different on visual inspection. The peak of activity in the morning of the healthy subjects is the reverse of the pattern shown by the dementia patients, whose activity rises steadily through out the day. Forced social factors such as ward routine are unlikely to account for the consistent rise in dementia patients' activity through the day. However, routines such as shopping or house work in the morning may explain the morning activity peak of healthy subjects.

The statistical analysis of activity epochs reflects the sizes of the observed differences on the graph. The most important result to be taken from this study is that severe dementia in-patients are substantially less active than healthy controls living in the community. This may be due, all or in part, to the dementia sufferers becoming

institutionalised or it may be intrinsic to the dementing process. Measuring the behaviour of dementia patients in the community would go some way to answering this question. However, dementia patients living in the community may be as restrained in their activities as those residing in hospital wards. Examining the relationship between dementia severity and activity levels with-in a community residing sample would elucidate the relationship better than a group comparison.

CHAPTER 5

The Measurement Of Behavioural Disturbance in a Mixed Severity, Community Living Dementia Sample through Activity Monitoring and Behaviour Rating Scales.

1. Introduction

Activity monitors have been shown to be fairly well tolerated by patients suffering from severe dementia. However, activity monitors could be less acceptable to less impaired patients who may wonder what the monitor is. Suspicion, paranoia and delusions are common in dementia patients (Rubin et al, 1987a; Patterson et al, 1990) and these ideas may be directed at the monitor. Therefore, a wide range of severity of community dwelling dementia patients were included in this sample to investigate whether the monitor^s were not suitable with any one type of patient.

In chapter 3 the study showed that "wandering", as rated by nursing staff, was significantly related to evening activity levels. No other ratings of behaviour could be used due to poor inter-rater reliability of other items on the rating scale. In this study carers living at home with dementia sufferers were asked to rate patient behaviour. Patients were only included in the study if their carers gave consent, therefore carers could be considered as willing to carefully rate patient behaviour. Two behaviour rating scales were included in this study, the Behaviour Rating Scale (BRS) of the Clifton Assessment Procedures for the Elderly (CAPE, Pattie and Gilleard, 1978) and the Revised Memory Behavior Problem Check-list (R-MBPC, Teri et al, 1989;1992) Both these scales have subscales which may measure disturbed-active and disturbed-

passive behaviours. These scales and their subscales were examined to ascertain whether they were measuring the same facets of behaviour and whether these rated behaviours reflected activity levels. Also it was postulated that some individual items of the R-MBPC (those considered to reflect over-active, under-active or night disturbance behaviours) would correlate with activity levels.

The CAPE scale gives a "dependency" score which reflects both low cognitive scores and high behavioural disabilities and behavioural problems. (The social disturbance subscale only contains 4 items and therefore accounts for little of the variance in the dependency score). It was postulated that activity levels would fall as dependency scores rise. The R-MBPC asked carers to rate to what degree each behaviour problem present were burdensome. It was predicted that behaviour problems resulting in greater activity from the patient would be rated as most burdensome by the carers. This should be reflected in greater activity values in patients whose carers' total care burden scores were highest.

Teri et al (1988), Rubin et al (1987a), Cooper et al (1989), Swearer et al (1989) and Burns et al (1990) showed a decline in cognitive abilities to be linearly related to an increase in some or all behaviour problems, both within samples and individuals. However, the correlations were small and the findings equivocal (Ballinger et al, 1988; Baumgarten et al, 1990; Ballard et al, 1991). Passive behaviours are at least as common as agitated behaviours and are included in the cognition-behaviour problem equation. It was expected that that cognitive scores decline as behaviour problems increase.

The study of activity levels in severe dementia patients indicated very low activity levels for most patients, although a small number of patients had high activity. It was

postulated that a decline in activity levels would occur as dementia progressed, except in patients who developed an activity related behavioural disturbance. It was predicted that a simple relationship between cognitive score and activity would not be evident due to confounding behavioural problems.

Degree of cognitive decline was taken to be equivalent to increasing dementia severity in this study. Although it is recognised that other aspects of behaviour make an important contribution to the staging of the disease, cognitive ability is the most commonly used marker for severity and it avoids tautology with the behavioural assessment aspect of the study.

Hypotheses:

- (1) Monitors will be accepted by all dementia patients, with a range of cognitive scores.
- (2) (i) The R-MBPC and BRS scales will correlate highly as will their subscales reflecting mainly disturbed-active and disturbed-passive behaviours. (ii) These scales and particular individual items of the R-MPBC will demonstrate a linear relationship with activity levels. (iii) "Dependency" scores will be inversely related to activity levels and a measure of carer burden will be positively related to activity levels.
- (3) Cognitive scores will be inversely related to collected ratings of behaviour problems.
- (4) (i) Activity levels will not demonstrate a significant relationship with cognitive decline. (ii) A decline in activity levels will occur as cognitive scores decline, except in patients who develop an activity related behaviour disturbance.

2. Method

2.1. The sample

Patients for this study were sought from four major sources. Case notes of attenders at the Jardine Clinic (Royal Edinburgh Hospital) and the Royal Victoria psychogeriatric day hospitals were examined and lists of potential subjects were vetted by the relevant consultants (see criteria below). This method finally provided only 12 patients who completed the study hence another consultant psychogeriatrician was approached for access to patients in the West Lothian district. Lists of possible subjects were provided by two Community Psychiatric Nurses working in the West Lothian region and by the Bangour Village Hospital psychogeriatric day unit, after meeting relevant staff and outlining criteria for selection. As for the study of severe dementia hospital in-patients, the medical records of such cases were checked to ensure the DSM-III-R criteria for dementia of the Alzheimer type or multi-infarct dementia were met. Subjects did not suffer from any concurrent illness which could significantly affect their mobility. Judgement as to whether a condition affected mobility was made in conjunction with medical staff. Patients with Parkinson's disease were excluded. Any other complaints were assessed individually: the severity, stability and impact on the patient were considered. All subjects lived with a carer. Severity of dementia was not specified.

Two patients were included who had been part of an Alzheimer's disease cohort investigated in previous research conducted by the Dementia Research Group at the University of Edinburgh Department of Psychiatry. Both these patients had been rigorously diagnosed as suffering from Alzheimer's disease, through numerous tests including computerised tomography scans and laboratory tests. These two patients

both had MMSE scores of 27 which may be considered to be within the range for questionable dementia or normality (Anthony et al, 1982). However, Kay et al (1985) have advocated that the MMSE is not effective in detecting mild dementia and the rigour of the diagnostic tests for the previous research trial were such that there can be very little doubt as to their condition.

2.2. Ethics and consent

Ethics approval for this study was obtained from the Lothian Health Board Psychiatry and Clinical Psychology Ethics of Medical Research Sub-Committee. Consent was sought from patients and carers following the procedure described in chapter 3. Letters were sent out to 73 households.

2.3. Instruments

Patients were assessed with the Cognitive Assessment Schedule (CAS) of the Clifton Assessment Procedures for the Elderly (CAPE), Pattie and Gilleard (1978) and the Mini-Mental State Examination (MMSE), Folstein, Folstein and McHugh (1975). Carers were assisted to fill in the Behaviour Rating Scale part of the CAPE and the Revised Memory and Behaviour Problem Check-list (R-MBPC) of Teri et al (1989). See appendix II for copies of these scales

The CAPE consists of a cognitive assessment and a behaviour rating scale for carers to fill in. The cognitive component measures the domains of information / orientation, mental ability (counting, alphabet, writing name and reading 10 words) and psychomotor ability (the Gibson spiral maze). The behaviour rating scale contains the sub-scales of physical disability, apathy, communication difficulties and social

disturbance. Copies of the CAPE forms and manual were purchased from Nefer Nelson, psychological test distributors. The manual provides normative data, profiles of varying impaired elderly populations and data on reliability and validity. A dependency grade can be worked out corresponding to both the cognitive and behavioural aspects of the scale.

The MMSE is brief, extensively used and validated method for assessing dementia (Anthony et al 1982, Folstein et al 1985). It measures orientation attention and concentration, short-term memory, calculation, the ability to name, write a sentence, follow verbal and written commands and copy a diagram. The total score of the MMSE may be 30 or 35 points if one uses both the items for concentration, that is both the serial sevens and spelling "world" backwards. Although these items may be measuring slightly different aspects of concentration, Mowry and Burvill (1989) point out that scoring 10 marks out of 35 would place a heavy loading on this one aspect of the test. My own clinical experience of the test is that serial sevens are very difficult and stressful for most subjects (even the relatively unimpaired) so only the "world" item was used for all subjects.

The CAS and the MMSE were the only tests of cognitive function to be used in this study. A large variety of psychological tests have been used with dementia patients, measuring a variety of cognitive domains. For this study however, the primary consideration was that tests were suitable for a wide range of dementia patients, from minimal to very severe deficit. Most of the test of specialised (e.g. Weschler logical memory test) or localised function (e.g. the stroop test for frontal lobe function) are aimed at not very impaired subjects and would not therefore distinguish the moderate to severe patients. My own clinical experience is that long psychological test batteries are very stressful and sometimes distressing to patients (and hence to carers also).

One of the assurances given to carers before consenting to the study was that the tests would be as brief as possible. For most of the items on the CAS and the MMSE it is possible to be tactfully vague about whether the patient has answered correctly and this helps to reduce the stress of testing.

The Revised Memory and Behaviour Problems Check-list was used by Teri et al (1989) in their study of behaviour problems in a community sample of mild to moderate dementia patients. This was one of the first of a number of new rating scales for behavioural problems in dementia, for use in a community sample. It has the advantage of a sensitive reporting style that includes data on the frequency of behaviour problems, not just their presence or absence and it also has a measure for caregiver response to the presence of each problem. At the time the R-MBPC was requested from its authors it contained 64 items. (The items and subscales have subsequently been revised (Teri et al 1992). The new scale is discussed in the results section).

2.4. Procedure

Patients and carers returning the slip of paper were contacted by telephone to arrange a visit to their home. Carers were asked to be present at the meeting. In the first instance an activity monitor was placed on the patient for 74 hours and record sheets for monitor removal were left, for the carer to complete if necessary, as described in previous studies. A further appointment was made to collect the monitor and carry out psychological assessment and obtain activity ratings. Copies of activity graphs and a letter of thanks (and a brief resume of the research, when requested) were sent to all participating households.

3. Results

3.1. Patient tolerance of activity monitors (Hypothesis 1)

Positive replies were received from 32 carers and patients. One carer decided not to help with the study when telephoned and two patients were admitted to permanent long-term care before they could be seen. 29 patients were visited and left with a monitor. 25 patients wore the monitor for the full 74 hours except for removal for washing etc (as shown by their record sheets). One carer removed the monitor from the patient at night because they thought it appeared uncomfortable and three other patients would not wear the monitor consistently for the prescribed time. These three patients were aged 94, 78 and 79, had MMSE scores of 18, 1 and 0, and two were females. Due to the small number of patients who would not wear the monitor and the wide range of cognitive scores, a comparative analysis with patients who would wear the monitor was not conducted.

3.2. Variables used in the analysis

The R-MBPC has recently been extensively revised by its authors (Teri et al, 1992) to contain 24 items in 3 subscales: memory-related, depression and disruption. These three factors are included as variables in the analysis, however some individual items from the earlier R-MBPC were kept in the analysis due to the probability of their reflecting activity disturbance. The items which make up the factors of the new R-MBPC and the individual items used are listed below.

Memory-related

forgetting recent events
repeated questions
losing things
forgetting the day
forgetting past events
reduced concentration
not finishing tasks

Disruption

verbal aggression
threats to hurt others
destroying property
behaviour dangerous to self or others
talking loudly and rapidly
embarrassing behaviour
arguing
waking up caregiver

Depression

comments about hopelessness
comments about being a burden
appears sad or depressed
comments about death
comments about being a failure
crying
comments about loneliness
appears anxious
suicidal threats

Individual items in analysis

fidgeting, pacing, fingering things
constantly restless
wandering about
spending long periods inactive
tired, fatigued
reversal of sleep patterns
sleeping less than usual
(waking up caregiver)

The variable of "care burden" consisted of the total score from the 64 items of the original R-MBPC.

The results of the MMSE and the CAS showed very similar scores and distribution, which suggests the two tests measure the same aspect of cognitive ability. This is demonstrated in the histograms of the two cognitive tests are displayed in figure 3.2.1 The MMSE score and CAS scores have a parametric correlation of 0.917. A new variable was created named "cognition" which consisted of the sum of the MMSE and CAS scores. This was used in place of the CAS and MMSE scores to reduce the number of variables in the analysis.

Figure 3.2.1. Frequencies of scores obtained by patients in the Mini-Mental State Examination and the Clifton Assessment Schedule.

MMSE		CAS	
0-1	* * * *	0-1	* * * *
2-3	* *	2-3	* * *
4-5		4-5	* *
6-7	* * *	6-7	* *
8-9	*	8-9	
10-11	* * *	10-11	* * *
12-13		12-13	*
14-15	* *	14-15	*
16-17	* * *	16-17	
18-19	* *	18-19	* * *
20-21		20-21	
22-23	*	22-23	*
24-25		24-25	* * *
26-27	* *	26-27	
28-29		28-29	
30		30-31	* *

The activity monitor data were processed in the same manner as described in the severe dementia in-patient study (chapter 3). It was divided into epochs for separate analysis of different times of day, based on the results from control data, reported in chapter 4. The period of rest or "night" was taken to be 4 hours from 0200 until 0600, when none of the controls were consistently active. Other epochs were chosen to reflect the likely periods between meal times and sleep. The morning epoch: 0800 until 1200, the afternoon epoch: 1400 until 1800 and the evening: 1800 and 2200. A variable of total activity for 72 hours is also considered.

Descriptive statistics of the major variables of the 25 completing patients are reported in table 3.2.2. Individual R-MBPC items are not included due to their restricted scoring range (0-4 only). Activity results are not included since the actual values have little meaning in themselves but serve as a method of comparison. Normal probability

graphs were plotted for each of the 16 variables in the table and the activity variables, and the Lilliefors and the Shapiro-Wilks tests were calculated to establish whether the variables conformed to normal distribution. These statistics test the hypothesis that the expected values from a normal distribution are different from those obtained in the current sample. Therefore a high probability value means that the obtained values do not conform to normal distribution. If either test gave a significant result at the 1% level the variable is listed as not normally distributed in table 3.2.2. A high level of significance ($P < 0.01$) is chosen for this assumption since most statistical tests are robust for variables borderline for normality (that is in the region $P < 0.05 > 0.01$).

Table 3.2.2. Table of minimum and maximum values, mean, median, standard deviations and distribution of major variables.

Variable	Min	Max	Median	Mean	StD	Norm Dist
Age	60	92	80	78.4	7.7	Yes
MMSE	0	27	10	10.2	8.6	Yes
CAS	0	30	10	11.8	9.9	Yes
Cognition	0	57	20	22.1	18.2	Yes
R-MBPC Total	2	84	52	47.5	23.5	Yes
Subscales:						
Depression	0	28	12	11.7	8.1	Yes
Disruption	1	29	16	15.7	8.3	Yes
Memory	0	28	24	20.1	8.8	No
BRS Total	1	27	19	17.0	7.6	Yes
Subscales:						
Physical disability	0	10	6	5.8	3.2	No
Comm disturbance	0	3	1	1.3	1.1	No
Apathy	0	10	7	6.3	2.8	No
Social disturbance	0	9	2	3.2	2.3	No
CAPE Dependency	1	9	8	7.0	2.5	No
Care burden	0	148	37	44.7	39.9	No

Abbreviations: Standard deviation (**StD**), Mini-Mental State Examination (**MMSE**), Clifton Assessment Schedule (**CAS**). MMSE+CAS= total cognition score variable (**Cognition**). Revised Memory and Behaviour Problems Check-list (**R-MBPC**), Communication (**Comm**), Clifton Assessment Procedures for the Elderly (**CAPE**). Normal distribution (**Norm Dist**).

The activity variables of morning, afternoon, evening and total activity show normal distribution but the night activity data are positively skewed

All of the variables used in the analysis gave a ratio or interval scale of measurement except for gender which had dichotomous categories. The major variables of activity values, cognition score and behaviour ratings did not show even vaguely bi-modal distribution and the sample size was small, thus correlation techniques were adopted for all tests other than gender analysis. Plots of the major variables against each other (activity-cognition, activity-behaviour, cognition-behaviour) showed either roughly linear relationships, or in a few cases, a nearly random relationship.

3.3. The effects of gender

12 patients were female, 13 were males. Two-tailed T-tests for independent samples were conducted between genders for the variables of age, cognition, BRS total, R-MBPC total, and morning, afternoon, evening and night activity values. These are reported in table 3.3.1 Mann-Whitney U tests were carried out on the non-normally distributed variables of care burden, dependency and night activity. See table 3.3.2.

Table 3.3.1 T-tests of differences in gender between the variables age, cognition, BRS total, R-MBPC total and activity variables.

Variable	Mean Female	Mean Male	t value	2-tailedProb
Age	78.67	78.15	-0.16	0.87
Cognition	19.58	24.46	0.66	0.51
BRS Tot	17.75	16.23	-0.49	0.63
R-MBPC Tot	54.92	40.62	-1.57	0.13
Morning	41640	36882	-0.43	0.67
Afternoon	34990	32384	-0.31	0.76
Evening	25627	21582	-0.83	0.42
Total activity	106560	96701	-0.42	0.68

Table 3.3.2 Mann-Whitney U tests for differences in gender between dependency scores, care burden and night activity.

Variable	Mean Rank Female	Mean Rank Male	U	2-tail Prob
Dependency	14.29	11.81	62.5	0.41
Care burden	13.75	12.31	69.0	0.65
Night activity	11.75	14.75	63.0	0.44

There were no significant differences between gender at the 5% level, for any of the variables in tables 3.3.1 and 3.3.2.

3.4. An analysis of behavioural measures (Hypothesis 2 i)

A comparison of the two behavioural measures and their subscales was conducted to see if similar aspects of behaviour were measured. The disruption subscale of the R-MBPC and the social disturbance subscale of the BRS are of particular interest, since it is postulated that these subscales are the most likely to reflect excess activity behaviours. The BRS subscale of apathy might be expected to measure a similar aspect of behaviour to the R-MBPC depression subscale, which may reflect decreased activity levels. Since the subscales of the BRS are negatively skewed in their distribution, non-parametric Spearman correlation co-efficients were calculated, both within and between scales. One tailed tests were used since it was expected that the number of behaviours reported will be positively related between subscales. The correlation coefficients are reported in tables 3.4.1, 3.4.2 and 3.4.3.

Abbreviations used in tables 3.4.1-3 : Behaviour Rating Scale total score (BRS Tot); Physical disability (Pd); Communication difficulty (Cd); Apathy (Ap); Social disturbance (Sd); Revised-Memory Behaviour Problem Check-list total score (R-MBPC Tot); Depression (Depress); Disruption (Disrupt).

Table 3.4.1. Spearman correlation coefficients and P values between subscales and total scores of the Behaviour Rating Scale.

	BRS Tot	Pd	Cd	Ap
Pd	.757 (P<.0005)			
Cd	.806 (P<.0005)	.630 (P<.0005)		
Ap	.732 (P<.0005)	.472 (P=.009)	.738 (P<.0005)	
Sd	.575 (P=.001)	.448 (P=.012)	.268 (P=.097)	.288 (P=.081)

Table 3.4.2. Spearman correlation coefficients and P values between subscales and total scores of the Revised-Memory and Behaviour Problem Check-list.

	RMBPC Tot	Depress	Disrupt
Depress	.914 (P<.0005)		
Disrupt	.946 (P<.0005)	.861 (P<.0005)	
Memory	.852 (P<.0005)	.626 (P<.0005)	.766 (P<.0005)

Table 3.4.3. Spearman correlation coefficients and P values between subscales and total scores of the Revised-Memory and Behaviour Problem Check-list and subscales and total scores of the Behaviour Rating Scale.

	BRS Tot	Pd	Cd	Ap	Sd
RMBPC Tot	.752 (P<.0005)	.833 (P<.0005)	.622 (P<.0005)	.528 (P=.003)	.717 (P<.0005)
Depress	.549 (P=.002)	.571 (P=.001)	.359 (P=.039)	.349 (P=.044)	.526 (P=.003)
Disrupt	.559 (P=.002)	.602 (P=.001)	.450 (P=.012)	.453 (P=.011)	.463 (P=.010)
Memory	.531 (P=.003)	.735 (P=.001)	.505 (P=.005)	.377 (P=.031)	.534 (P=.003)

Table 3.4.1 shows that the subscale of social disturbance does not correlate significantly at the P<0.01 level with either of the three subscales in the BRS, where as the other subscales inter-correlate highly. Table 3.4.2 reveals that the memory subscale has the lowest inter-correlations of the three subscales in the R-MBPC, although even the lowest correlation is significant at the P<.0005 level.

The correlation coefficients between subscales of the R-MBPC and BRS are all significant at the P<0.05 level, although 5 of the 20 correlations are not significant at

the $P < 0.01$ level. The correlations between the subscales social disturbance (BRS) and disruption (R-MBPC) and between apathy (BRS) and depression (R-MBPC) are .463 and .349 respectively, which means there is substantial variance unaccounted for between these subscales.

**3.5. The Relationship between activity values and behavioural ratings
(Hypothesis 2 ii)**

The total scores from the behavioural measures reflect both active and passive behaviours, hence there is no reason to postulate a particular direction of relationship between these scores and activity values. As the night activity variable had a skewed distribution, all statistics were non-parametric. The activity variables for morning, afternoon, evening, night and total activity were correlated with the behavioural measures of the total BRS score and the total R-MBPC score with a two tailed, Spearman's correlation test, in table 3.5.1. All correlations are very low and none of the values are significant at the $P < 0.05$ level.

Table 3.5.1. Two-tailed Spearman's correlation co-efficients between activity variables of morning, afternoon, evening, night and total activity and the total behavioural scores from the BRS and the R-MBPC.

	Morn	Afternoon	Evening	Night	Total
BRS Total	-.310 ($P=.132$)	-.105 ($P=.618$)	-.056 ($P=.792$)	.272 ($P=.188$)	-.171 ($P=.413$)
RMBPC Total	.074 ($P=.724$)	.149 ($P=.479$)	.080 ($P=.704$)	.146 ($P=.488$)	.093 ($P=.658$)

(1) It was postulated the following variables would correlate positively with all activity variables. Since these items did not specifically state at which times these behaviours should occur, in order to be rated to be present, night time activity is also compared.

Variable	Abbreviation used
1. fidgeting, pacing, fingering things	agitation
2. constantly restless	restless
3. wandering about	wanders
4. disruption factor	disrupt
5. social disturbance factor	soc dist

(2) It was postulated the following variables would correlate negatively with day time and total activity variables. These variables clearly cannot refer to night time behaviour (except sleep reversal - see below).

Variable	Abbreviation used
6. spending long periods inactive	inactive
7. tired, fatigued	tired
8. reversal of sleep patterns	sleep rev
9. depression factor	depress
10. apathy factor	apathy

(3) It was postulated the following variables would correlate positively with the night activity variable:

Variable	Abbreviation used
11. reversal of sleep patterns	sleep rev
12. sleeping less than usual	sleep less
13. waking up caregiver	waking CG

These correlations were performed with one tailed Spearman's (nonparametric) correlations. The results of these correlations can be found in tables 3.5.2, 3.5.3 and 3.5.4.

Table 3.5.2. One-tailed Spearman's correlation coefficients for activity variables and probable active behaviours.

	Morn	Afternoon	Evening	Night	Total
Agitation	.086 (P=.342)	.402 (P=.023)	.242 (P=.123)	.127 (P=.273)	.252 (P=.111)
Restless	-.159 (P=.223)	.152 (P=.234)	.080 (P=.352)	.043 (P=.416)	.018 (P=.467)
Wanders	.071 (P=.368)	.284 (P=.084)	.113 (P=.295)	-.214 (P=.152)	.154 (P=.232)
Disrupt	-.010 (P=.481)	.110 (P=.310)	.055 (P=.398)	.236 (P=.128)	.053 (P=.400)
Soc dist	-.043 (P=.420)	.055 (P=.396)	.063 (P=.382)	.080 (P=.352)	-.002 (P=.496)

Table 3.5.2 shows there are no relationships between the "disturbed" subscales from the BRS and the R-MBPC and the activity scores. The wandering and restlessness items from the R-MBPC also show random correlations with activity. The agitation variable, which asked for ratings of fidgeting, pacing and rubbing does correlate significantly with afternoon activity at the 5% level, although other activity variables do not reflect this association.

Table 3.5.3. One-tailed Spearman's correlation coefficients for activity variables (excluding night) and probable inactive behaviours.

	Morn	Afternoon	Evening	Total
Inactive	-.203 (P=.166)	-.028 (P=.447)	-.045 (P=.416)	-.123 (P=.280)
Tired	-.298 (P=.074)	-.157 (P=.226)	-.080 (P=.352)	-.208 (P=.159)
Sleep rev	-.021 (P=.460)	-.060 (P=.388)	-.079 (P=.353)	-.048 (P=.410)
Depress	-.057 (P=.393)	.054 (P=.398)	.056 (P=.395)	-.007 (P=.487)
Apathy	-.325 (P=.056)	-.046 (P=.413)	-.066 (P=.377)	-.161 (P=.222)

Table 3.5.3 shows no significant correlations with any variable and activity at the $P<0.05$ level. However, correlations tend to be in the predicted direction and tend to be larger in the morning.

Table 3.5.4. One-tailed Spearman's correlation coefficients for night and total activity variables and night associated behaviours.

	Night
Sleep rev	.256 (P=.109)
Sleep less	.324 (P=.057)
Waking CG	.140 (P=.252)

None of the three measures of sleep disturbance correlate significantly with the night activity variable, although the "sleeps less than usual" variable is approaching

significance with a correlation of 0.324.

3.6. The relationship of care burden and dependency to activity monitor values (Hypothesis 2 iii)

It was predicted that behaviour problems resulting in greater activity from the patient will be rated as most burdensome by the carers. This should be reflected in greater activity values in patients whose carers' total care burden scores were highest. The dependency score of the BRS reflects both low score on the CAS and high scores on the BRS. This combination of low cognitive score and high physical dependency, communication disorder and apathy predicts lower activity values (the social disturbance items contribute little variance to the over all BRS level and do not correlate with high activity, as demonstrated above). A negative correlation coefficient is predicted with activity. Table 3.6.1 shows the one-tailed Spearman correlations for care burden and dependency.

Table 3.6.1. Spearman correlation coefficient and their probability values for a one-tailed test between activity variables and care burden and dependency.

	Morn	Afternoon	Evening	Night	Total
Care	.159 (P=.225)	.384 (P=.029)	.285 (P=.083)	.054 (P=.399)	.227 (P=.138)
Dependency	-.341 (P=.048)	-.233 (P=.131)	-.074 (P=.362)	.250 (P=.114)	-.233 (P=.132)

The care burden variable has a significant correlation with afternoon activity at the 5% level and the dependency variables reaches this level of significance with the morning

activity variable.

3.7. The relationship between cognition scores and behavioural variables (Hypothesis 3)

It was predicted that cognitive scores would be inversely related to behaviour problems, as measured by the rating scales, in total and by subscale totals. One-tailed Spearman correlation coefficients are computed for the rating scales, in total and for subscale totals and the cognition variable, in table 3.7.1.

Table 3.7.1. One-tailed Spearman correlations and significance values for cognition, R-MBPC total, BRS total and all subscale totals.

Variable	Cognition	Variable	Cognition
R-MBPC Tot	-.311 (P=.065)	BRS Tot	-.577 (P=.001)
Disrupt	-.581 (P=.001)	Social dist.	-.129 (P=.270)
Depress	-.602 (P=.001)	Apathy	-.687 (P<.0005)
Memory	-.176 (P=.200)	Commun diff.	-.605 (P=.001)
		Physical dep.	-.681 (P<.0005)

Table 3.7.1. shows that high scores on the disruption and depression factors are significantly correlated to cognitive decline, at a probability level of less than 1%. The memory factor is not significantly related to the cognition score and this factor's contribution to the R-MBPC total score gives the latter a small correlation with cognition which is not significant at the $P<0.05$ level. The BRS total has a high

correlation with cognition scores, as do the subscales of apathy, communication difficulties and physical disability. The social disturbance subscale has a very low correlation with cognition scores, which is not significant. Overall, most of the behaviour rating subscales correlate highly with cognitive decline, however "depression" and "social disturbance" do not.

3.8. The relationship between activity variables and cognition scores (Hypothesis 4 i)

It was postulated that activity values would not be related to the variable of cognition. These correlations were performed with one tailed parametric correlations, The results of these correlations can be found in table 3.8.1.

Table 3.8.1. One-tailed parametric correlation coefficients between cognition and activity variables.

	Morn	Afternoon	Evening	Night	Total
Cognition	.313	.218	.056	-.330	.209

None of the above correlations are significant at the $P<0.05$ level, supporting the hypothesis that cognition and activity values do not show a significant relationship.

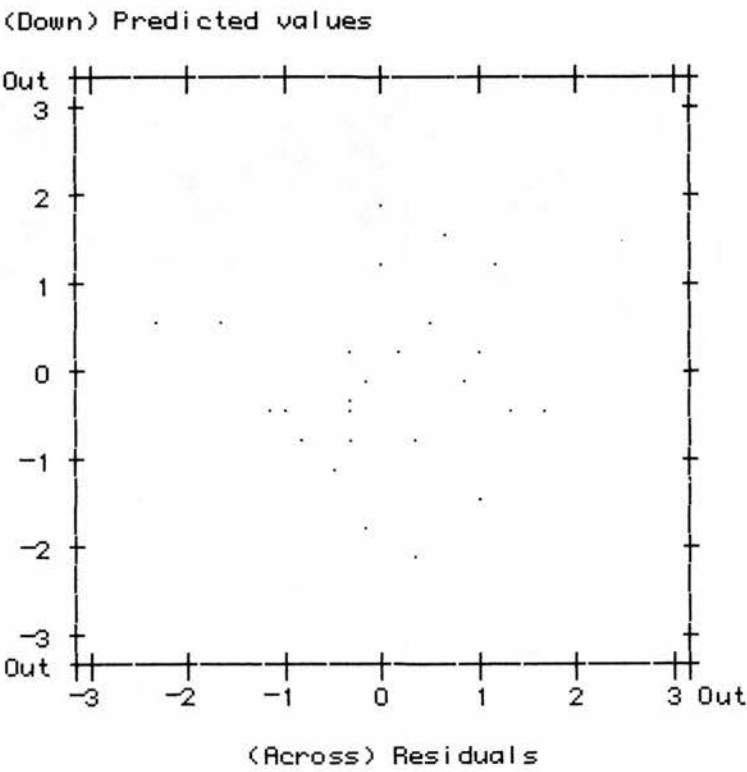
3.9. The relationship between activity, cognition and behaviour ratings (Hypothesis 4 ii)

The hypothesis states that the relationship between activity and cognition will be complicated by certain individuals who have particular, high activity behavioural problems. Likewise the relationship between activity and behaviour disturbance will

be affected by the cognitive ability of subjects. The parametric correlation of disruption with afternoon activity is .116, however when a partial correlation is calculated which partials out the effects of cognition the resulting correlation is .643. Partial correlations can only be performed with variables which show normal distribution. To test inter-relationship of all the variables, some of which do not conform to normal distribution, it is necessary to conduct linear regression analysis, for which certain assumptions have to be met.

The dependent variable must show normal distribution. The variable cognition meets this requirement and is the dependent variable in all equations. The variables must be linearly related, which was previously established. A further test of the type of relationship, other than plotting variables against each other, is to look at the residual values which are left once the regression equation is fitted. If a regression model is appropriate for the data, there should be no relationship between the predicted values and the residual values. A plot of the residuals against predicted values in the regression equation of cognition and activity by the disruption variable, is presented in figure 3.9.1. This shows there is no relationship present, which also indicates the assumption of equality of variance is also met. If the assumption of equality of variance had not been met the spread of the residuals would have increased or decreased with the predicted values.

Figure 3.9.1. A plot of the residuals against predicted values in the regression equation of cognition and morning activity by the disruption variable.



Variables in the regression equation must be independent, therefore only one activity variable is entered into each equation, since these variables can be considered repeated measures. If independent variables in the equation correlate highly (high multicollinearity) large standard errors are produced and partial regression co-efficients are less likely to be significant. Some of the behavioural measures, especially some individual items from the R-MBPC correlate very highly together. To avoid high multicollinearity each behavioural variable is entered into a separate equation. Behavioural variables 1 to 5 are regressed against activity variables morning, afternoon, evening and night . Behavioural variables 6-10 are regressed against morning, afternoon and evening. Behavioural variables 11-13 are regressed against

the night variable alone. The activity variable of "total activity" is not entered into any equations. From previous correlations it has been shown to be a compromise result between the day time variable and the night time variable. The "total activity" variable adds no new information to the analyses.

Each regression analysis generates a regression line and statistics showing how well the data fit. The R^2 is the coefficient of determination, which reflects the goodness of fit in the sample. R^2 tends to be an over optimistic estimate of fit for a population so an adjusted figure which takes into account the number of variables, is provided (adjusted R^2). An Analysis of Variance (ANOVA) test is conducted for each regression equation to test for a linear relationship between the dependent variable (cognition) and combined set of independent variables. The ANOVA test generates an "F" value and a level of significance for that value, which indicates if the linear regression model is appropriate. The degrees of freedom for the ANOVA are 2 for the regression and 22 for the residual values, in all equations conducted.

Each of the independent variables has a standardized partial regression coefficient labelled "Beta". The method of entry for the independent variables in these equations is forced, which means they are added simultaneously. However, for each variable a "T" value is calculated which is the square root of the "F" value of the ANOVA for the contribution of that particular variable to the regression model (with the effects of the other independent variable partialled out). The significance of the T value (labelled "Sig T" in the tables below) shows whether the contribution of each independent variable may be considered statistically significant.

Each table below contains the results of several regression analyses. For each equation the adjusted R^2 (Ad R^2), the "F" value from the combined independent

variables ANOVA and the significance of the F value are given (Sig F). The Beta coefficients, "T" values and the significance of the T value are given for each of the two independent variables in the equation (Sig T). Table A-E contain the regression analyses of the over-active behaviour variables with morning, afternoon, evening and night activity variables.

Table A. Variable : Disruption factor

	Morn. / Disrupt		Aft. / Disrupt		Even. / Disrupt	
Ad R2	.428		.395		.270	
ANOVA F	9.97		8.82		5.43	
Sig F	.001		.002		.012	
Beta	.400	-.620	.365	-.648	.109	-.575
T	2.56	-3.98	2.24	-3.97	.62	-3.28
Sig T	.018	.001	.036	.001	.539	.003

Table A cont. Variable : Disruption factor

	Night / Disrupt	
Ad R2	.286	
ANOVA F	5.81	
Sig F	.009	
Beta	-.172	-.511
T	-.95	-2.82
Sig T	.352	.010

Table B. Variable : Social disturbance						
	Morn / Sd		Aft. / sd		Even / Sd	
Ad R2	.117		.091		-.001	
ANOVA F	2.59		2.20		.996	
Sig F	.098		.135		.386	
Beta	.349	-.306	.325	-.362	.115	-.289
T	1.81	-1.59	1.60	-1.78	.553	-1.38
Sig T	.084	.127	.125	.090	.586	.180

Table B cont. Variable : Social disturbance		
	Night / Sd	
Ad R2	.052	
ANOVA F	1.66	
Sig F	.214	
Beta	-.267	-.161
T	-1.24	-.745
Sig T	.229	.464

Table C. Variable : Pacing, fidgeting, unable to sit still. (Agitation)

	Morn / Agit.		Aft. / Agit.		Even / Agit	
Ad R2	.160		.159		.018	
ANOVA F	3.28		3.27		1.22	
Sig F	.057		.057		.313	
Beta	.396	-.372	.431	-.477	.145	-.324
T	2.06	-1.94	2.06	-2.28	.69	-1.54
Sig T	.051	.065	.052	.033	.498	.138

Table C. cont. Variable : Agitation

	Night / Agit.	
Ad R2	.078	
ANOVA F	2.02	
Sig F	.157	
Beta	-.280	-.221
T	-1.39	-1.10
Sig T	.178	.284

Table D. Variable : Constantly restless.

	Morn / Rest.		Aft. / Rest.		Even / Rest.	
Ad R2	.203		.203		.103	
ANOVA F	4.07		4.06		2.38	
Sig F	.031		.032		.116	
Beta	.321	-.415	.329	-.484	.106	-.421
T	1.76	-2.28	1.76	-2.59	.546	-2.16
Sig T	.092	.033	.093	.017	.590	.042

Table D. cont. Variable : Constantly restless.

	Night / Rest.	
Ad R2	.181	
ANOVA F	3.40	
Sig F	.043	
Beta	-.288	-.376
T	-1.55	-2.03
Sig T	.136	.055

Table E. Variable : Wandering.

	Morn / Wand		Aft. / Wand		Even / Wand	
Ad R2	.124		.146		.070	
ANOVA F	2.71		3.05		1.90	
Sig F	.089		.068		.174	
Beta	.236	-.393	.277	-.416	.074	-.380
T	1.23	-2.05	1.45	-2.18	.38	-1.93
Sig T	.230	.052	.160	.040	.711	.067

Table E. cont. Variable : Wandering.

	Night / Wand	
Ad R2	.231	
ANOVA F	4.60	
Sig F	.021	
Beta	-.396	-.436
T	-2.19	-2.41
Sig T	.040	.023

Tables A-E show that out of the behavioural variables of disruption, social disturbance, agitation, restlessness and wandering, only the disruption variable combines with any activity variables to give an enhanced linear relationship with cognition. The ANOVA s show significant linear relationships at the 1% level for the morning and afternoon variables. The standardized partial regression coefficients "Beta" are significant for both morning and afternoon activity variables at the 5% level. The restlessness variable combines with activity variables to give a weak linear relationship with cognition (morning, afternoon and night F values, $P<0.05$) but the contribution made by the activity variables is small (T values are not significant e.g. morning Beta, $P=.092$).

Tables F through to J contain the regression analyses of the under-active behaviour variables with morning, afternoon, evening activity variables. The night time activity variable is not included since these behaviours could not be appropriately rated for during the night (except sleep reversal, which is treated separately below).

Table F. Variable : Spending long periods inactive.

	Morn / Inactive		Aft. / Inactive		Even / Inactive	
Ad R2	.080		.038		-.020	
ANOVA F	2.05		1.47		.77	
Sig F	.153		.252		.476	
Beta	.309	-.243	.238	-.266	.061	-.249
T	1.58	-1.24	1.18	-1.33	.29	-1.21
Sig T	.129	.228	.249	.199	.772	.239

Table G.. Variable : Tired or fatigued

	Morn / Tired		Aft. / Tired		Even / Tired	
Ad R2	.084		.052		.012	
ANOVA F	2.11		1.66		1.14	
Sig F	.146		.214		.337	
Beta	.265	-.255	.200	-.290	.038	-.302
T	1.33	-1.28	.98	-1.45	.19	-1.49
Sig T	.120	.214	.336	.160	.855	.151

Table H. Variable : Reversal of sleep patterns.

	Morn / Sleep		Aft. / Sleep		Even / Sleep	
Ad R2	.051		-.019		-.078	
ANOVA F	1.64		.78		.14	
Sig F	.216		.473		.874	
Beta	.359	-.184	.243	-.138	.057	-.095
T	1.74	-.90	1.16	-.66	.27	-.45
Sig T	.094	.380	.260	.516	.790	.658

Table I. Variable : Depression factor.

	Morn / Depress		Aft. / Depress		Even/ Depress	
Ad R2	.382		.364		.222	
ANOVA F	8.43		7.87		4.42	
Sig F	.002		.003		.024	
Beta	.408	-.587	.397	-.634	.122	-.537
T	2.51	-3.61	2.34	-3.74	.67	-2.
Sig T	.020	.002	.029	.001	.507	.007

Table J. Variable : Apathy.

	Morn / Apathy		Aft. / Apathy		Night / Apathy	
Ad R2	.525		.535		.489	
ANOVA F	14.24		14.80		12.49	
Sig F	.001		.001		.001	
Beta	.190	-.694	.210	-.725	.047	-.727
T	1.32	-4.85	1.51	-5.21	.33	-4.98
Sig T	.200	.001	.146	.001	.748	.001

The single items from the R-MBPC, inactivity, tiredness and sleep reversal do not combine with any activity variables to form a linear relationship. The apathy subscale of the BRS correlates highly with cognition by itself and the partialling of apathy score leaves the activity variables not contributing to the regression fit.

Table K gives the regressions analyses results for the night time behavioural ratings of sleep reversal, sleeping less and waking up the caregiver, all with night activity only.

Table K. Variables: Sleep reversal. - Sleeping less. - Waking caregiver.

	Night / Rev.		Night. / Less		Night / Waking	
Ad R2	.031		.123		.520	
ANOVA F	1.38		2.68		14.02	
Sig F	.273		.091		.001	
Beta	-.354	.057	-.120	-.362	-.122	-.703
T	-1.59	.26	-.51	-1.54	-.82	-4.75
Sig T	.125	.801	.613	.137	.420	.001

The sleep reversal rating and the sleeping less rating do not combine with the night activity variable and cognition variable to produce a linear relationship, since the F values are very low. The behavioural rating for "waking up the caregiver" has a linear relationship with cognition and activity but the activity variable does not enhance the relationship, as shown by the significance of the T value.

In summary, the regression analyses show the partialling of the "disruption", "wandering" and "Depression" variables, alone, enhance the relationship between cognition scores and any of the activity monitor values.

4. Discussion

4.1. Patient tolerance of activity monitors

Hypothesis (1) stated that monitors would be accepted by all dementia patients, with a range of cognitive scores. This has been largely born out, with 25 patients accepting a monitor and only 3 refusing to wearing one. The 3 patients who would not tolerate a monitor were not of one "type", two patients falling into the severe category from their MMSE scores (0 and 1) and one falling into the moderate range (18). The carers of these patients did not think their relative would find the monitor unacceptable, any more than did any of the relatives of patients who would tolerate a monitor. These 3 patients did not apparently make accusations or suffer from irritability any more than the other patients. The reasons for the 3 patients not to tolerate wearing a monitor are unknown.

4.2. Variables used in the analysis

Teri et al, (1992) revised the version of the Revised Memory and Behaviour Problem Check-list (R-MBPC) they used in their 1989 study. The 64 items present in the previous version were reduced to ensure a reasonable subject to item ratio, with their sample of 201 geriatric patients. Three psychologists sorted the 64 items into three categories, postulated a priori to be important: memory-related, depression and disruption behaviour. Sorting by raters and tests for multiple correlations then factor analysis of the remaining items, finally left 24 items in the scale.

Although these methods will have undoubtedly produced a rating scale with a greater internal reliability it does not necessarily follow that the validity of the scale will be increased. This method of selecting items for a behavioural scale presupposes that the behaviours of interest form a coherent group, presumably with some central causal factor. An examination of the items left in the scale shows that many items which often appear most frequently in prevalence studies, such as wandering, pacing and restlessness have been omitted from the new scale. The new "disruption" factor contains 4 (out of 8 items) reflecting verbal behaviour. The "depression" factor also contains primarily verbal reports from the patient of feeling depressed. In the later stages of dementia speech may be incoherent or lost altogether (DSM-IIIIR, 1987). This scale was constructed with the ratings of a sample of mixed cognitively impaired and mood disturbed patients, with an mean MMSE score of 19 (standard deviation of 6.3, range 0-29). This may account for emphasis attached to verbal behaviour in depression and disruption sub-scales. Although verbal behaviour may reflect physical behaviour, this cannot be assumed a priori, so the items of the previous R-MBPC pertaining to increased or decreased physical activity were used as separate items in the analysis.

Retaining a number of individual items from the 1989 R-MBPC means that the number of variables in the analysis will be very high considering the small number of subjects. The Bonferoni principle states that as the number of variables examined increases the likelihood of obtaining spurious results also increases. Rather than not use some of the information collected during this study a cautious approach will be adopted to the acceptance of individual significant results. The cognition scores from the MMSE and the CAS were sufficiently similar in absolute scores and distribution that the two variables were amalgamated to create one cognition variable.

4.3. The effects of gender

This sample contains an unusually high proportion of males (13) to females (12). There are more older females in the general population than males and this difference is usually reflected in dementia populations. The most common carer of a dementia patient is a spouse, or secondly a daughter. It may be that women are more predisposed to assist with research projects. An analysis of sex differences was conducted on the major variables. The two-tailed tests for significance revealed no differences between the two groups.

4.4. An analysis of behavioural measures

A comparison of the two behavioural measures and their subscales was conducted to see if similar aspects of behaviour were measured. Hypothesis (2) (i) stated that the R-MBPC and BRS scales would correlate highly as would their subscales reflecting mainly disturbed-active and disturbed-passive behaviours.

In the BRS scale, the subscale of social disturbance does not correlate significantly at

the 1% level with either of the three subscales in the BRS, whereas the other subscales inter-correlate highly. In the R-MBPC scale, the memory subscale has the lowest inter-correlations of the three subscales in the R-MBPC, although even the lowest correlation is significant at the $P < .0005$ level. The R-MBPC appears to be a more homogeneous scale than the BRS. The correlation between the depression and disruption subscales is very high (0.86), suggesting that either a common factor of behavioural change is being measured by these two subscales, or there is a rating bias towards reporting the presence of behavioural change in this scale. The hypothesis that the disruption and depression subscales will reflect high and low activity respectively appears unlikely in the light of this high correlation.

It might be expected that the subscales of social disturbance from the BRS and disruption from the R-MBPC measure similar aspects of behaviour. However the correlation observed of 0.46 is one of the smallest correlations between subscales. Similarly the potentially similar subscales of apathy (BRS) and depression (R-MBPC) correlate at only 0.35. These two correlations are smaller than most of the other subscale correlations for which a less close relationship might be expected. It can be concluded that the social disturbance and disruption subscales do not both equally measure a single cluster of behaviours which is discrete from that which is measured by the other items in the scales. This is also the case for the apathy and depression subscales.

4.5. The Relationship between activity values and behavioural ratings

Hypothesis (2) (ii) stated that various behavioural measures would demonstrate a linear relationship with activity levels. As the night activity variable had a skewed distribution, all statistics computed were non-parametric correlations. This was

to allow a comparison between the different activity variables and errs on the side of caution. The total scores of the BRS and R-MBPC contain a combination of items that may reflect both high and low physical activity. Ratings of these behaviours may cancel each other out in the relationship with activity values. As expected, the rating scale total scores do not correlate significantly with any of the activity variables.

Active-disturbed measures. The correlations between the social disturbance and disruption subscales and the activity scores are not significant. This may be because the items in these subscales do not refer specifically enough to disturbed-active behaviours such as wandering or pacing. However, the wandering and restlessness items from the R-MBPC also show very low correlations with activity. The agitation variable, which asked for ratings of fidgeting, pacing and rubbing does correlate significantly with afternoon activity at the 5% level, although other activity variables do not reflect this association. **Passive-disturbed measures.** The subscales of depression and apathy do not display a linear relationship with activity values, neither do the individual items of inactivity, tiredness or sleep reversal. **Sleep-disturbed measures.** The ratings for items sleep reversal, sleeping less and waking the caregiver do not correlate significantly with the night time activity variable.

The low correlations observed between most of the behavioural measures and the activity variables suggests the activity measure does not reflect behaviour that can be simply quantified by carer ratings. The most common method of assessment for behaviour problems is by carer ratings. "Behavioural disturbance" is behaviour which is disturbing and therefore a subjective component is implied. In a case of disagreement between objective and subjective measurement of behavioural disturbance^{iv} is probably the objective measure which is not measuring the required phenomenon. However, this does not mean that the ratings of behaviour by carers

are the absolute gold standard by which all other measures should be judged. The measurement of activity may prove a more accurate measure of behaviour in individual patients in which the behaviour has been pre-identified as disturbed. These results suggest that the measure provided by activity monitoring alone may not be sufficient to make judgements about the behavioural problems of a group of dementia sufferers.

4.6. The relationship of care burden and dependency to activity monitor values

It was postulated that behaviour problems resulting in greater activity from the patient will be rated as most burdensome by the carers. The "care" variable reflects the overall burden score from all 64 items from the 1989 version of the R-MBPC. There is a significant positive correlation between the care measure and afternoon activity; other epochs are not significant. Thus the hypothesis is supported to the limited extent that of the four correlations with activity only the afternoon activity relates significantly with carer burden. This may reflect overall higher agitation in the afternoon.

In this work, individual care ratings were not examined, in order to keep the number of variables to a minimum. However, a more accurate estimate of whether more active-disturbed behaviours are more burdensome to carers would be achieved by looking at the individual care ratings associated with the active-disturbed behaviours such as the agitation variable.

It was predicted that the dependency score would be associated with lower activity values since the dependency score is a combination of low cognitive score and high

physical dependency, communication disorder, apathy. and social disturbance scores. Although it was postulated the social disturbance score would correlate positively with activity values, this subscale contains only 4 items and hence does not make a large contribution to the "dependency" score. Also, the social disturbance score has been shown not to correlate significantly with activity so it should not affect the dependency-activity relationship.

The dependency score correlates negatively with increasing activity for the morning epoch only at the 5% level. This complements the afternoon-care burden correlation, in that activity appears to increase in the afternoon, enhancing the relationship of passive-type behaviours and morning activity levels.

4.7. The relationship between cognition scores and behavioural variables

Hypothesis (3) stated that cognitive scores would be inversely related to ratings of behaviour problems. Of the R-MBPC, the depression and disruption subscales showed high correlations with cognition (both over 0.5), but the memory subscale has a low correlation which is not significant. This may seem surprising since this scale measures memory loss, which is the most common, progressive symptom of dementia. However, the behaviours measured by this scale (e.g "forgetting which day it is") are so intrinsic to dementia that all carers of patients, regardless of the stage of dementia, probably report them as common occurrences. The R-MBPC total score reflects the compromise between the three factors and does not achieve significance at the 5% level.

The apathy, communication difficulties and physical dependency subscales all

correlate highly with cognition scores (all over 0.6). Social disturbance has a very low correlation with cognition. This result is in keeping with the observation that this subscale does not sample from the same larger group or type of behaviours which the rest of the scale measures. The subscales of apathy, communication difficulties and physical dependency, contain a mixture of items but many of them are measures of the ability to perform tasks of every day living. That is, they measure functional deficit.

These results show that most behavioural problems, functional, depressive and disruptive, occur more frequently with increasing cognitive impairment in patients suffering from senile dementia. The correlations obtained for the subscales showing this relationship are high, demonstrating a strong link between the two measures. The relationship between individual behaviours and cognition and individual patients and particular behaviours may be complicated by unmeasured variables. However, the association in this sample between an increased number of behaviour problems with increased cognitive impairment is strong.

4.8. The relationship between activity variables and cognition scores

Hypothesis (4) (i) stated that activity levels would not demonstrate a linear relationship with cognitive decline. The null hypothesis that activity levels and cognitive impairment would show a significant relationship was rejected. However, the correlations demonstrate a trend for a linear relationship which may demonstrate a statistically significant relationship with a larger sample size.

4.9. The relationship between activity, cognition and behaviour ratings

Hypothesis (4) (ii) stated that a decline in activity levels would occur as cognitive

scores decline, but that this relationship would be complicated by a group of patients who develop an activity related behaviour disturbance. This hypothesis was tested by regression analysis, which allows the goodness of fit of a linear relationship to be examined between two variables (cognition and activity), with the influence of the other (behavioural) variable partialled out. The various behavioural measures were regressed against selected activity variables. For most of the variables the activity measure did not enhance the relationship between cognition and the combined variance from the behavioural and activity variables.

The activity variables for morning and afternoon show a significant linear relationship with cognition in the regression analyses with the R-MBPC factors of depression and disruption. The night activity variable shows a linear relationship with cognition when the wandering ratings are accounted for. Morning and afternoon almost show a significant relationship with cognition with the agitation rating partialled, but this is not quite significant at the 5% level. The significance levels of the "T" ^uvalue are low for all these equations. although "T" may be significant at the 5% level it does not mean that the linearity of the relationship is very strong. The adjusted R² for the equation with the best fit, that of morning/cognition/disruption, is only 0.43 which means under half the variance is accounted for by the model.

4.10. Summary

The wearing of activity monitors was acceptable to most patients, although three individuals (about 10% of the sample) persistently removed their monitor. The subscales of social disturbance and disruption did not assess a uniform factor of disturbed behaviour, hence they are unlikely to both reflect a type of "disturbed-active" behaviours as measured by activity monitoring. The activity measure for the

afternoon showed a significant linear relationship to the rating of the agitation variable, which rated the behaviours: "fidgeting, unable to sit still, pacing, fingering objects." Neither social disturbance or disruption subscale ratings were associated with increased activity values. No other behavioural variable showed a significant correlation with activity.

There was a strong relationship between most of the behavioural subscales and cognition; only memory and social disturbance did not show this association. The relationship between day time activity and cognition was enhanced when the ratings for the factors of depression and disruption were partialled out. This was also the case for night activity, cognition and the wandering rating. However these associations were weak. Overall the measurement of activity does not clearly reflect ratings of behaviour and does not show a clear change in relation to disease severity, as measured by cognitive impairment. The measure of activity levels may prove most appropriate in conjunction with an initial subjective evaluation of a behavioural problem. The grouping of activity data for a sample may not make the best use of this data. The information provided by the activity graphs of individual patients across changing conditions may be useful for clinical evaluation.

CHAPTER 6

The Behavioural Consequences of Neuroleptic Medication Withdrawal in Severe Dementia Hospital In-patients.

1. Introduction

The studies reported in chapters 3, 4 and 5 used the method of comparing activity levels between groups to look for differences. In order to do this data were lumped together which obscured information about individual cases. Monitoring for change in activity of individual patients through a treatment regime may be an appropriate use of this technology. In the following experiment a within patient design is used.

A number of reviews concerning the efficacy of antipsychotic / neuroleptic use in the treatment of behavioural problems in dementia appeared in the late 1980s (Helms, 1985; Raskind et al, 1987; Salzman, 1987; Sunderland & Silver, 1988; Small, 1988). All the authors comment on the lack of well designed trials although the consensus is that drug treatments show some limited efficacy.

Schneider, Pollock and Lyness (1990) conducted a meta-analysis of 33 controlled trials of neuroleptic treatment in dementia. As previously reported, neuroleptics were found to be more efficacious than placebo, although the analysis suggests that only 18% of patients benefited from treatment, over that of placebo. This, combined with potentially serious side-effects such as tardive dyskinesia (an involuntary stereotyped movement disorder, Jeste & Wyatt, 1982) leads authors to propose the judicious use of antipsychotics with the elderly.

The elderly patient has less efficient metabolism of drugs and often receives medication for a number of complaints simultaneously, increasing the risk of drug interaction and unacceptable side-effects (American Psychiatric Association, 1980). Stephen and Williamson (1984) reported that half the patients referred to a geriatric unit with Parkinsonian symptoms had the effect caused by drugs. Wilson and MacLennan (1989) commented that drug induced Parkinsonism is "more common, more complicated and a less benign condition than is generally realised," giving rise to a poor prognosis. There has been controversy in the United States over whether the use of psychotropics in long term care of the elderly is a form of treatment or merely control (Mann et al, 1984) and many authors have commented on the seemingly excessive use of drugs for behavioural problems, especially in long term care environments (Thomas, 1988; Ray, Federspiel & Schaffner, 1980; De Leo, Stella & Spagnoli, 1989).

The cumulative evidence on the limited success of neuroleptic treatment and the high risk of side-effects that may be as severe as the original behavioural complaint suggests that many dementia patients may receive medication unnecessarily. The following study therefore examines the effectiveness of neuroleptic use through medication withdrawal in dementia patients who have been receiving medication for long periods of time. This design was selected since the periodic re-assessment of drug effectiveness is considered good medical practice and likely to be accepted by an ethics committee as of potential benefit to the patient.. The initial design type is AB only, with the decision as to whether the patient should remain off medication or be resumed being left to the patient's consultant.

Several rating scales for the assessment of behavioural disturbance in dementia

were available for use in this study, such as the Revised Behavior Problem Check-list (Teri et al, 1989) and the Behavioral Pathology in Alzheimer's Disease Rating Scale (Reisberg et al, 1987). However, due to the problems with nurse compliance reported in chapter 3, it was decided to conduct behavioural assessments which did not require nursing time.

Behavioural observation was chosen as the method of assessment most likely to measure small changes in behaviour. Most rating scales only record the frequency of behaviours over a few points on a scale and this may not be sensitive enough to pick up changes in already agitated patients. Naturalistic observations of behaviour, in situ, have the advantage of not interfering with usual routine and environmental variables which may be important determinants of behaviour. In the interests of impartiality and for the assessment of reliability it was decided to record behaviour by video camera for later analysis by two different "blind" observers.

Hypotheses:

- (1) Withdrawing neuroleptic medication will have no effect on agitated behaviour.
- (2) The activity monitor results will reflect directly observed behaviour in any signs of change.

2. Method

2.1. The sample

Subjects were sought from three different Lothian hospitals: the Royal Edinburgh

Hospital and the Royal Victoria Hospital in Edinburgh and Herdman Flat Hospital in Haddington. Patients were selected from ten psychogeriatric long stay wards, housing approximately 250 patients.

Initial selection was made from case notes and in consultation with ward Charge Nurses, Registrars and Consultants. The criteria for suitability were as follows. Initially notes were checked for the diagnosis of dementia, either Alzheimer type or multi-infarct dementia, made previously by the consultant. The full medical records of such cases were checked to ensure the DSM-III-R criteria were met for primary degenerative dementia of the Alzheimer type or multi-infarct dementia. Some of the medical records were deficient in some aspects of information required, but a policy of exclusion by the presence of contra-indication was followed. Thus subjects could not all be rigorously diagnosed as suffering from either Alzheimer's disease or multi-infarct dementia, but there was no evidence to suggest their symptoms were caused by other medical or psychiatric conditions. This was to ensure a sample of patients with typical presentations of either of the two most common dementias.

All patients met the DSM-III-R criteria for severe dementia in that their "activities of daily living are so impaired that continual supervision is required, e.g. unable to maintain minimal personal hygiene; largely incoherent or mute." Subjects were receiving a stable dose of neuroleptic medication for the treatment of behaviour problem(s). The stability of the treatment was a subjective evaluation made by a ward doctor. No stipulation was made as to whether the treatment was successful since various degrees of efficacy were reported from no effect to radical behaviour change, although a moderate effect was most common.

2.2. Ethics and consent

Ethics approval for this study was obtained from the Lothian Health Board Psychiatry and Clinical Psychology Ethics of Medical Research Sub-Committee. The major ethical consideration in this study is whether medication withdrawal is likely to cause harm or discomfort to patients and whether this risk is acceptable in light of the potential benefits to the patients involved. The evidence on the limited efficacy and potential side-effects of the medications in question is summarised above. The experimental design takes the patients' comfort as paramount throughout the procedure. An extra assurance was made to relatives concerning the use of video film of patients. It would not be shown to anyone not directly involved with the study and all film would be destroyed after the completion of the analysis of the tapes.

Suitable patients had letters sent to their next of kin. Included with the introductory letter were an information sheet explaining the procedure and a consent form with a stamped addressed envelope for reply. If no reply was received after several weeks ward staff were asked to mention the project to relatives when they visited patients on the ward to assess their attitude toward the project. If the relative was interested in the patient taking part they were approached a second time to obtain consent. A description of the sample finally included in the study is given in section 3.1.

2.3. Procedure

When relatives' consent was obtained for two patients on the same ward one was randomly allocated to the experimental group, the other acted as a matched control. Both patients had an activity monitor placed on their nondominant wrist

for 72 hours and record sheets were placed with the ward staff as described in chapter 3.

After the completion of the 72 hours activity recording the monitors were removed. The patient in the experimental group was then withdrawn from medication received for behaviour disturbance. The medications stopped include thioridazine, haloperidol. and droperidol.

The drug clearance rate was calculated for each compound in advance. This was done by the convention of multiplying the drug half life by 5 times and then doubling this time. A second period of activity recording and filming was undertaken either when the clearance time was up or when staff reported a decline (increase in agitation) in either of the patients' behaviour. A more formal method of nurses recording behaviour was not considered necessary. Any nursing or medically significant decline in behaviour would ethically require treatment to be resumed, hence the notification of this requirement was considered a robust measure. Any improvement in behaviour would probably continue until the formal recording date and would not necessitate an early assessment. Records were always made of both patients on the same days. If a decline in the control patient prompted an assessment then another recording would be made when the drug clearance time was up. If no changes in behaviour were noted then a second observation phase was carried out in 2 weeks and again in another 2 weeks if necessary.

2.4. Behavioural analysis

Patient behaviour was filmed by camcorder for analysis at a later date by two independent observers. In the first instance the requirements for a representative

sampling procedure for filming were assessed. Although there is a body of literature concerning the prevalence of behaviour problems there are no studies of how often episodes of behavioural disturbance occur in the very short term. It was therefore necessary to establish approximately how many behaviours per patient might need to be looked at and how frequently behaviours occur during a day and over a number of days.

Three patients were observed who had been given a diagnosis of senile dementia, by their consultant. The patients were residents from two of the wards described above. They were carefully picked in consultation with ward staff to ensure that they were fairly typical of adversely disturbed dementia patients in the ward. Preliminary talks with these staff revealed that most patients were fairly consistent with their day to day degree of disturbance, although it was believed that over the course of a month a patient could show signs of fairly major change. Each patient was observed continuously for three days from 10.00am until 5.00pm with breaks of 15 minutes morning and afternoon and an hour over their lunch period. A short hand notation was quickly developed in situ, to describe the patients' current behaviour and whereabouts on the ward. Whilst formally recording the behaviours of the three chosen patients, other clearly disturbed patients were informally observed. This was done during periods of inactivity or sleep of the patient under study. Napping was seen to be common in many patients. Waking behaviour was found to be highly predictable for the three individual patients. Most of the patients were observed to indulge in a restricted number of behaviours over the three days.

The decision on video sampling was governed by several considerations. Filming was carried out during one complete day. This allowed for two or more days consecutive filmings as separate observational periods should the rate of

behavioural change warrant it. The day chosen was the second day the activity monitor was worn. On the first day it was ensured the monitor was acceptable to the patient. If, after drug withdrawal, behaviour change was reported by staff, then filming would commence on the first full day after reporting. The activity monitor would be placed on the patient the same day as filming, in this instance. A time period for filming was chosen which gave a balanced view of patient behaviour without being so long the rater would lose concentration. Each compact video tape lasts 30 minutes and due to the restricted variation in behaviour of these patients, 30 minutes was judged to be an adequate period for observation. In order to get a good sample of behaviour during the day each patient was filmed 5 times for 6 minutes. Staff expressed a preference that filming should be restricted to the less busy times of day when a nurse could be sure to be available to help with any problems. Video recording took place during 10-11am, 11-12noon, 2-3pm, 3-4pm, 4-5pm, with approximately 55 minutes between consecutive hours. These times ensured all patients were in their day time routine and avoided all meal breaks.

An essential component of behavioural analysis is the use of behaviour coding systems or check-lists. This arises from the need to limit what is observed to manageable levels or accuracy and reliability may suffer (Foster & Cone, 1980). As previously reported, the type of problem may vary considerably between patients which would require either a different coding system for each patient or a more general assessment of agitation. Some behaviour observation instruments exist for the assessment of activity (e.g Eaton, Enns & Presse, 1987) but these have mostly been developed for use with hyperactive children. Ulrich and Harms (1985) developed a complex coding system to monitor which parts of a subject's body were moving and whether the movement was purposeful or not. Fisch et al (1983) used a code to determine changes in a series of positional states over time.

However both these coding systems were developed for use over short periods of time; only three minutes (Fisch et al, 1983) or eight minutes (Ulrich and Harms, 1985). To use such complex codes over a more prolonged period would quickly tire the observers and adversely affect the reliability of the measure. Again, the range of activities shown by severe dementia patients varies considerably between patients, although less so within patients. The observers were requested to rate both activity and agitation (defined below) separately to examine whether one of these best reflects what is being measured by the activity recording.

Two independent untrained observers rated pairs of video clips for change. The observers watched 6 minutes of a clip from one session followed by 6 minutes from the other session. Rater one saw the first recording session before the second; rater two watched the films in reverse order. After each 6 minute clip the observer was asked to rate whether the second film they watched showed more or less over all activity and more or less restlessness. Subjects were asked specifically:

"Please pay attention to two particular aspects of the patients behaviour.

(1) Consider how much physical movement the patient makes, including how much they sit or walk and how much they move their arms or hands.

(2) Consider how many of their movements do not have a specific, recognisable goal. For example, moving an arm to pick up a cup of tea is goal orientated where as continually rubbing a table top may not be. Movements which appear to have no goal can be a reflection of restlessness or agitation."

If the rater detected any difference in activity or restlessness they were requested to use a "1" to denote a slight difference and a "2" for an obvious difference, noting the appropriate direction of change. The raters watched 5 pairs of clips for

each of the 6 subjects. The activity graphs were rated with the same convention, both for the full 3 days and for the one day when the filming took place.

3. Results

3.1. Subjects

Of the 250 patients on the psychogeriatric wards, letters requesting consent were sent to 36 patients' relatives. Of these 12 positive replies were received. Two of these patients were on individual wards from which only one agreement was obtained hence no control was available. One patient was found to be suffering from a serious concomitant illness (carcinoma) between initial selection and projected commencement of the study and one patient was withdrawn from their neuroleptic medication without warning before the start of the study. 4 pairs of patients began the initial behavioural assessment of the protocol. One patient would not tolerate the activity monitor and since no other patient could be found to replace them only 3 pairs continued to the drug withdrawal phase of the study.

Due to the small number of patients completing the study, each patient withdrawn from medication and their control are described as separate case pairs. This method of reporting helps highlight the methodological problems encountered in this study.

3.2. Case descriptions

The three days activity graphs of the all six subjects, for both conditions are presented in appendix III. The activity graphs of each subject for the day filming

took place for both conditions are presented in figures 3.1.1, 3.1.2 and 3.1.3. Each figure shows activity for a pair of subjects with the first activity measurement on the top half of the page and the post medication withdrawal date on the bottom half of the page.

Pair number 1 (figure 3.1.1) consisted of two female patients with very severe dementia, EW and AB. Both were unable to perform any usual tasks of daily living and were unable to walk unaided. EW's behaviour disturbance consisted of agitation, mostly shouting and deliberately falling onto the floor. AB was mute but very agitated which manifested by shaking her limbs about and repetitive rubbing and rocking in her chair. AB was withdrawn from droperidol (30 hours clearance). Staff reported a deterioration in AB's behaviour the following evening. It was claimed that she was more agitated, in the same manner as before. Activity monitors were placed on both patients and video filming was carried out the next day. The activity monitors were left on for the full 72 hours although AB resumed her medication the evening of day 1, after filming.

Pair number 2 (figure 3.1.2) were also females with severe dementia, HG and CL, although both were reported to be able to walk unaided. HG and CL made occasional utterances although they were nonsensical or out of context; CL also repeatedly called out "cigarette". HG indulged in persistent wandering and some repetitive behaviours such as rubbing or hand wringing. CL was reported to shout out and indulge in repetitive rubbing or waving of her hands. HG had her medication of thioridazine stopped. After the drug clearance date, a behaviour analysis was conducted on the two patients, with no report of behaviour change from staff. HG was suddenly put back on medication before the next assessment was due and before the recommencement was reported to the author.

Pair number 3 (figure 3.1.3) consisted of two males with very severe dementia, TM and GT. Both TM and GT were unable to speak coherently, unable to perform any usual tasks of daily living and were unable to walk unaided. Both received medication for agitation which consisted mainly of shaking their arms and occasional shouting out or wailing. GT was withdrawn from his medication of haloperidol although a night time dose of thioridazine was not stopped as it was felt by medical staff that this would be too likely to adversely affect the patient. The staff reported an exacerbation of GT's agitation two days before the calculated drug clearance date (16 days) and activity monitoring and video filming were carried out the next day. Unfortunately GT suffered a fatal cerebral accident the following day, although medical staff believed this to be unrelated to the study conditions.

Figure 3.1.1. Activity graphs for the days of video filming for experimental subject AB, followed by control subject EW.

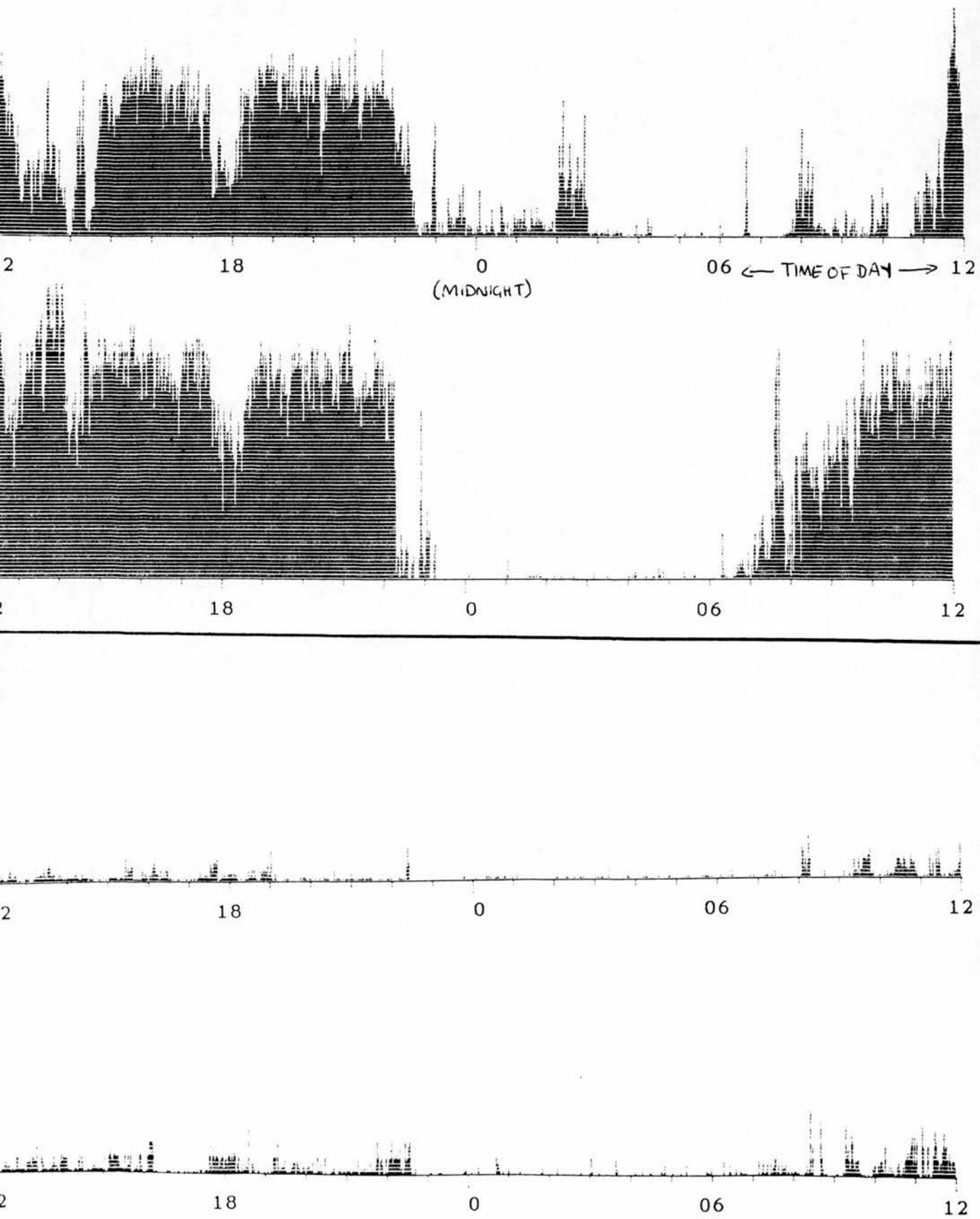


Figure 3.1.2. Activity graphs for the days of video filming for experimental subject HG, followed by control subject CL.

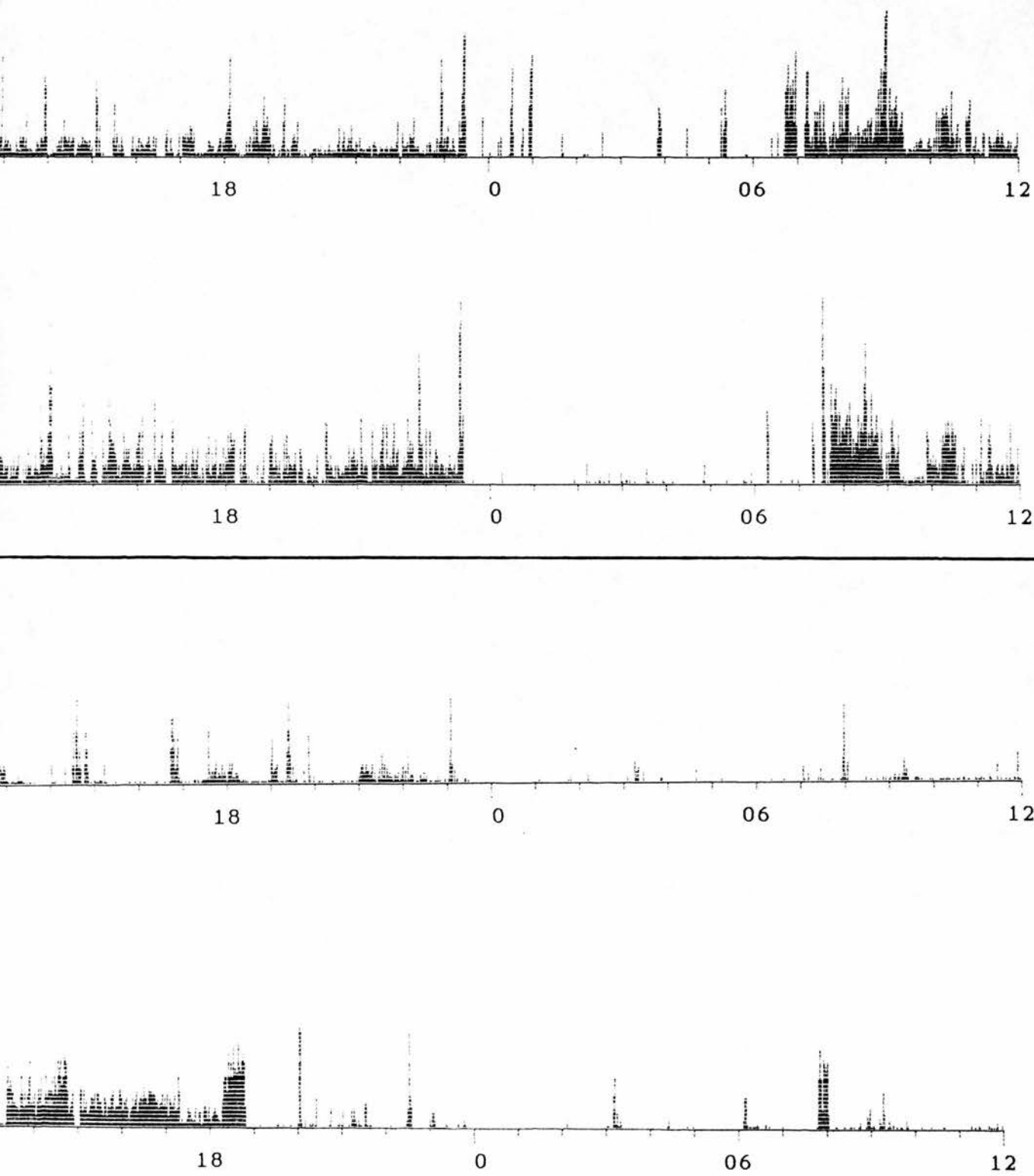
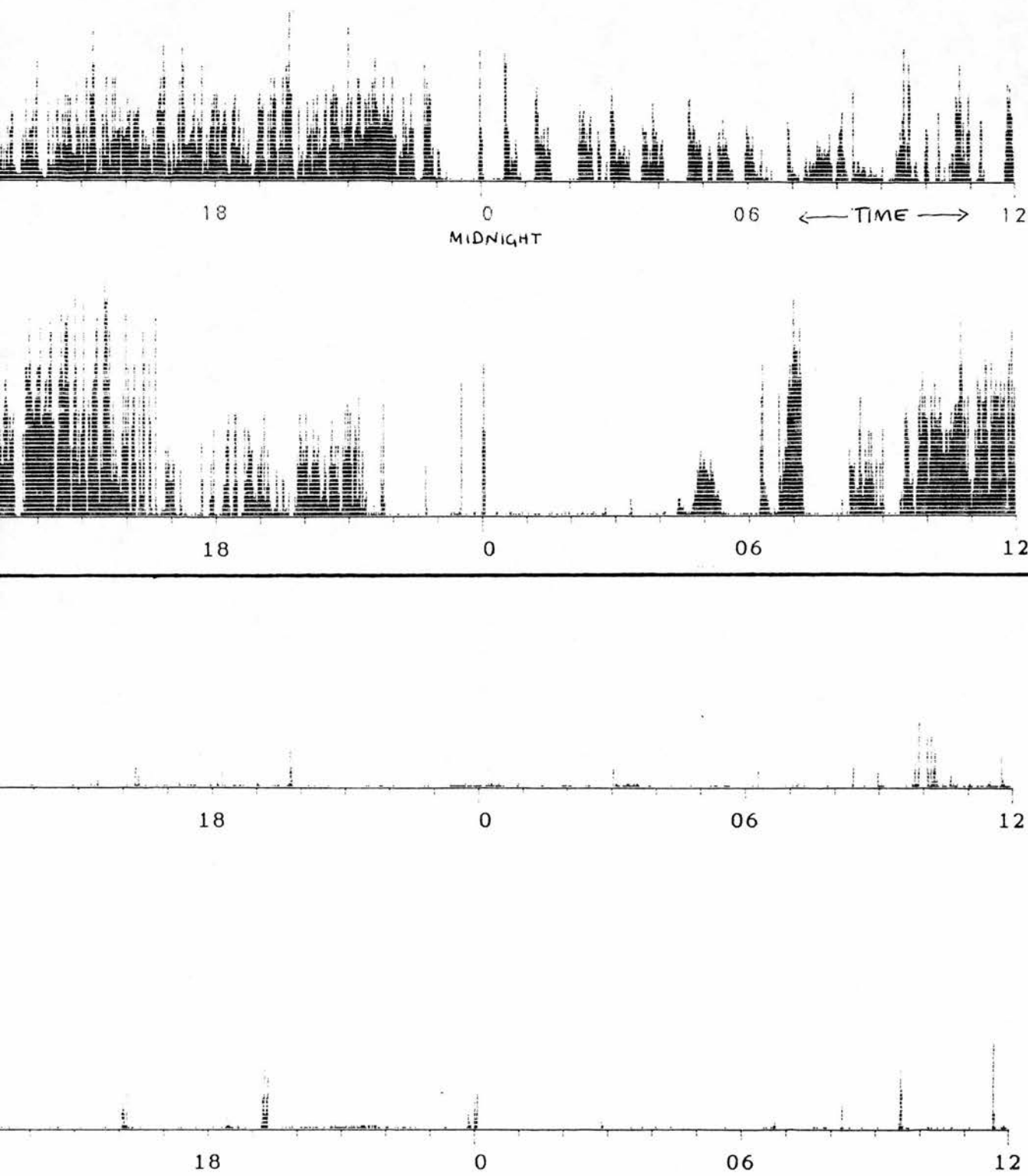


Figure 3.1.3. Activity graphs for the days of video filming for experimental subject GT, followed by control subject TM.



Due to the small number of patients found suitable, or consented for the study and the attendant problems described above it was decided not to pursue this study any further. The data collected were analysed for comparison of (any) change in the video clips and the activity graphs. The hypothesis about the effects of drug withdrawal is not tested due to insufficient numbers of patients.

3.3. Behavioural observations

The ratings of both observers are reported in table 3.3.1 The ratings for the 5 clips per patient have been summed to give an over all rating for the half hour of behaviour. The figures show how much of the behaviour sampled in the second video clip is different from that in the first clip, thus a high figure need not reflect a large change in the quality of the agitation, but may reflect a change in the quantity. With this method random changes, of a positive and negative nature, are largely cancelled out. The table shows the summed ratings for filmed behaviour on the left side of the table and ratings for the activity graphs on the right half. Of the film ratings, the "activity" rating of observer 1 (Ob 1) is given first followed by the activity rating of observer 2 (Ob 2). These are followed by the "restlessness" ratings, again first by observer 1 followed by observer 2.

The three patients above the black mid-line are the patients whose medication was stopped, the three below are control patients. As reported above, patients AB and GT were reported by nursing staff to be more agitated on the second assessment. Patient HG was not reported to be more agitated on the second assessment although a week later she was returned to her original medication.

Table 3.3.1. Behavioural and activity ratings of change by two observers with three experimental subjects and three controls.

	Summed Video Ratings				Activity Graph Ratings			
Patient	Activity		Restlessness		3 Days Activity		Video Day	
	Ob1	Ob2	Ob1	Ob2	Ob1	Ob2	Ob1	Ob2
AB	+5	+7	+7	+6	+2	+2	+2	+2
GT	+2	+7	+9	+8	+2	+2	+2	+2
HG	+10	+2	+8	+2	0	0	-1	-1
EW	+1	+2	+2	+1	0	+1	-1	-1
TM	0	0	0	+2	0	0	0	0
CL	0	+1	+1	+1	-1	-1	0	+1

3.4. Inter-rater reliability of video observations

Hereafter the term "patient" is used to describe the three subjects in the experimental condition; other subjects are referred to as "controls". The two observers show good agreement on their ratings of the three controls and patient AB, which is concordant with nursing assessment. Patient GT is given similar ratings to AB by observer 2, although observer 1 makes the one and only clear distinction between total activity and restlessness with this case; rating GT as consistently more restless in the second assessment but not consistently more active. Patient HG shows the greatest disagreement between the two raters. Although both concur with an increase in activity and restlessness in the second

assessment, the ratings of +2 by observer 2 are so small as to be unlikely to be significant.

3.5. Inter-rater reliability and internal consistency of activity graphs

The visual ratings of the activity graph show good agreement between the observers. Ratings for the full 3 days are in perfect agreement with the video recording day for three subjects for both observers. These are the patients who show the most consistent change (AB & GT) and the control who shows the most obvious lack of change (TM). Both observers agree HG shows no change overall and a slight decrease on the day of videoing. Out of 12 ratings there only two disagreements between the observers: on both occasions (EW, CL) only a "slight" difference is noted.

3.6. Comparison of video analysis and activity graphs ratings

As for the inter-rater consistency, the best agreement between the two assessments occurs with the patients showing greatest (AB, GT) and least (TM) change. The most obvious discrepancy occurs between the activity / restlessness and activity graph ratings for HG, particularly for observer 2, showing a much larger than expected amount of error.

4. Discussion

4.1. Subject numbers

There are several possible causes attributable to the low patient numbers in this

study. Firstly, dementia sufferers were required to be resident in hospital so that the appropriate medical monitoring could be carried out. Carers may have not been able to cope with any potential changes in behaviour.

Secondly, the number of patients on the psychogeriatric wards examined was surprising low. Although many of the patients met the criteria for dementia and a large number received medication for behavioural problems, the treatments were frequently not of long standing. It transpired that many patients who develop behaviour problems have had a number of treatments tried on them. If one treatment does not work they will usually be given an alternative treatment, until doctors find the most appropriate drug. Ward staff also claim that behavioural problems are often episodic in nature, as reported by Cumming et al (1982).

This factor of behavioural change combined with the dynamic treatment of individuals meant that few patients were available who had been on the same medication for more than a few weeks. It was considered necessary that treatment should be stable before the commencement of the study so that any change in behaviour would be attributable to the interventions of this study. A specific criterion for "stable" was not stated by the author as it was felt preferable that medical expertise should decide this. This may have excluded a number of potential subjects, on the side of caution.

Ward routines vary, sometimes substantially, especially between hospitals, so controls were required to be obtained from the same wards as experimental subjects. Thus at least two patients had to be found from any one ward, which further reduced the number of patients in the study. For example, one of the patients in a matched pair did not tolerate the monitor and no replacement could be found from that ward, hence both patients were lost from the study.

Of the 36 relatives written to about the study, only one third replied. No negative replies were received but this was expected since only a positive reply slip was posted out, for return by next-of-kin. This study was specially designed with the comfort of the patients as the primary consideration and these precautions were explained to relatives on an information sheet. However, it is possible that the patients next-of-kin considered the study more likely to cause discomfort to the patient than accrue any benefits to them. An attempt to follow up some of the carers who did not reply by telephone was made, with the permission of the relevant consultant but this did not prove fruitful.

4.2. Problems encountered during the study

One of the patients (HG) in the drug withdrawal phase of the study was recommenced on medication without prior notice to the author. An attempt was made to prevent this situation by familiarising all ward staff with the aims of the study and leaving the author's home telephone number, to be contactable at any time. Patients in this study were from the same wards as those in the severe dementia in-patient study (chapter 3). Possibly staff lost interest in this line of research over the two years it was conducted.

Although one of the subjects died during the course of the study, medical staff were of the opinion that it was not related to the interventions of the study. However, after this incident, combined with the extreme problems with patient numbers, it was decided to not carry out any further investigations.

4.3. Inter-rater reliability of video observations

The inter-rater reliability for video observations was good overall. "Activity" and "restlessness" were rated as the same except for observer 1 for one case. Raters were asked to write down any general comments at the end of rating a patient for the two conditions. For the incident of disagreement between activity and restlessness ratings, observer 1 said that the type of activity was much the same for the two conditions, but the patient grimaced and wailed more in the second condition. This was taken as an indication of distress thus the patient was rated as similarly active but a lot more restless. For observer 1, greater activity was synonymous with greater restlessness but greater restlessness was observed in the presence of equal activity, in one case. For observer 2 the two categories appeared inter-changeable.

Overall, activity and restlessness are virtually synonymous in these severely impaired patients. From the lengthy observations made on the wards, described in section 2.4, very little active behaviour was observed to be directed towards any goal. It appears that too great a quantity of any behaviour becomes a nuisance to other patients and staff and hence becomes a behavioural problem. However, facial expression and vocal behaviour are also important indicators of distress in a patient.

The rating system used is consistent between conditions, except in one case where the degree of change is small (HG). The rather coarse method of measuring change is likely to be responsible for this anomaly. In cases with a large change (AB GT) or very little or no change (the controls) the agreement is good. If observer 1 perceived a small but consistent difference in HG and observer 2 either did not perceive a difference or thought it too small to warrant rating as change,

then a fairly large difference in total scores could ensue. HG's main behaviour is walking up and down the wards. It may be difficult to assess a small change in speed, for example, without very careful observation.

4.4. Inter-rater reliability and internal consistency of activity graphs

The ratings for the three days and for the video day are consistent except for some ratings of "slight" differences (2 cases out of 12 ratings were "slight" disagreements). These probably reflected differences between raters' judgements of the activity graphs rather than real differences in behaviour since the two raters do not agree on the "slight" differences noted. The agreement between the observers is complete, apart from the two cases noted above, indicating the activity graphs have good inter-rater reliability for visual inspection.

4.5. Comparison of video analysis and activity graphs ratings

The best agreement between raters for the differences between the two conditions occurs with the cases of greatest (AB and GT) and least (TM) change. As noted before for the reliability of the video analysis, the greatest discrepancy occurs with the borderline case, patient HG.

Agreement might be improved by developing a more sensitive method for coding behavioural change. The current method fails to distinguish between the size of any changes and the constancy of change, which can result in large amounts of error, as in the case of HG.

4.5. Summary

This study examined the usefulness of activity graphs for measuring activity change in patients who had been pre-selected as suffering from agitation in dementia. The activity graphs showed high internal consistency and good agreement between raters as to their indication of change or lack of change in activity levels. A method was developed for assessing the filmed behaviour of subjects, which had the advantage of applying to all patient behaviours, but which was not very sensitive. The inter-rater reliability for video assessment was good for the patients who showed the greatest and least degrees of change and this was reflected in the agreements between video and activity graphs.

Visual inspection of activity graphs to assess changes in activity levels is a reliable and valid method of measurement in cases of fairly clear change. The assessment of behavioural problems needs^{to} contain a subjective component to monitor the complicated interaction of patient behaviour and environmental considerations. The use of activity graphs in conjunction with carer evaluation could provide additional information on patient behaviour, particularly of use for times when the carer is absent for limited periods.

CHAPTER 7

Conclusions

A review of the literature established that behavioural disturbance in dementia can be viewed in the context of increased or decreased activity levels. Accelerometers provide an objective, quantitative method for measuring activity and allow continuous non-labour intensive monitoring. When this work commenced there were no published reports of the use of solid-state activity monitors with dementia patients. This new technology and the usefulness of the type of data generated had not yet been addressed with respect to behavioural problems in dementia. Thus, this thesis was primarily a feasibility study. The studies described here investigated the reliability and validity of activity monitors as measures of disturbed behaviour in dementia sufferers.

1. Overview

Preliminary work was carried out to examine the properties of different types of accelerometer to find the one most suited for use with dementia patients. The study reported in chapter 3 established whether wearing an activity monitor was acceptable to some or all dementia sufferers. Normative data was collected to assist with the decision about the best method of data analysis. The activity patterns of a large group of controls was examined and compared to the dementia sample. The validity of monitoring activity for the assessment of behavioural disturbance was examined by comparing ratings of behaviour to activity levels in

a mixed severity group of dementia patients. This study also examined the association between degree of cognitive decline, behavioural ratings and activity levels. A final study looked at the effects of medication on agitation in severe dementia patients. This with-in patient design examined the possible degree of behavioural and activity change within individuals.

2. Sample size

The size of sample required for an experiment can be calculated in advance, provided some initial information is available. One needs to have an estimate the size of difference expected, or at least decide how large a difference would be required to be meaningful or significant. With this research the size of potential differences in the measure of activity were completely unknown, both between individuals and groups. Therefore the sample sizes in this work were dictated by practical considerations. In practice the sample sizes for all groups, except the drug withdrawal study, were around 25 subjects.

The access to patients for research is primarily through medical practitioners. Dementia patients who live in the community often have contact with their General Practitioner, but no other medical personnel. Obtaining referrals from GPs can be a slow process as they are only likely to refer patients who come to their attention at the time of the study. Also GPs may not wish to refer patients to a study which has no obvious benefits for the patient.

It was decided to recruit patients from doctors who specialized in the treatment or assessment of dementia patients, therefore consultant psychogeriatricians were approached. This method was most appropriate for the study of severe dementia patients, since the more severe the dementia the more likely a patient is to be

referred either to a day hospital, respite care or long term care. The community sample consisted of patients attending day hospitals and patients of community psychiatric nurses. The sample was biased towards the more cognitively impaired but showed a reasonable range of severities, especially with the addition of the two mild cases from a previous Alzheimer's disease research project.

Six consultant psychogeriatricians were approached for access to patients in the Lothian Region. Further access to patients would have necessitated going out with the Lothian region which would have been impractical in terms of travelling time. The lack of suitable patients in Lothian Region can be attributed to concomitant medical pathology and lack of carer assent to patients' inclusion in a study.

3. Diagnoses

The diagnosis of dementia was not so specific that it excluded large numbers of patients (eg only probable Alzheimer's disease, with rigorous criteria). As previously discussed, the behaviour of patients diagnosed with Alzheimer's disease is not markedly different from those diagnosed with multi-infarct dementia. Although Pick's disease and frontal lobe dementia cases show more pronounced behavioural disturbance earlier in the course of the disease, these conditions are rare and would be difficult to diagnose without substantial medical resources which were not available to this study.

However, patients with senile dementia are elderly, by definition and frequently suffer from concomitant medical complaints which would exclude them from study. Any serious medical complaint, such as coronary heart disease or carcinoma, is likely to affect mobility, especially if the patient is confined to bed.

Other complaints may adversely affect mobility such as arthritis and Parkinson's disease and patients with these conditions had to be excluded.

4. Ethics

Medical ethical principles are based on the attempt to compromise the needs of the individual patient and the needs of research to benefit society as a whole, although it is usually the individual who has primary consideration (Kendell, 1989). The issues are particularly difficult when the subject of a study cannot give their informed consent. Although a patient may appear to have no objections to the procedures in a study they can only give informed consent if they understand what is being done and why and that they are not obliged to take part, if they do not wish to. While dementia sufferers in the early stages of the disease may be able to understand it is unlikely that patients with moderate or severe dementia will be capable of giving informed consent. The Royal College of Physicians (1984) suggested that in cases where informed consent could not be obtained "the agreement of the immediate family - whether spouse, parent, adult offspring or sibling - should be sought". Family members may give "assent" to include a patient in a research study.

In the above studies the assent of next of kin of all dementia patients was sought; in addition the consent was sought from patients in the community study. This consent was undoubtedly informed in some cases but not in the more severe cases. Although many carers of dementia patients wish to assist with research, in the hope of furthering knowledge of the dementia syndrome, many carers did not reply to requests for assent. Letters were sent requesting permission rather than personal visits as it was felt letters would be less coercive. Although carers were sent information sheets which explained the procedure for each study, personal

contact may have been more successful at reassuring carers that the interests of the patient would be paramount.

5. Activity monitors

Several types of human activity monitor have become commercially available over the last five years or so. A preliminary investigation revealed no important differences in information processing but monitors varied in size and cost. The Gaehwiler monitor was the smallest and cheapest model available and five were purchased for this work. Obtaining the activity monitors from the manufacturer in the first instance took considerable time. The monitors were individually made to order. There were problems obtaining the VAT free status accorded to medical and research equipment, due to the high cost of the monitors exceeding certain limits. (Gaehwiler Electronic is a Swiss company, hence subject to non EC importation restrictions). The first batch of three monitors was held by HM Customs and Excise for six weeks while the appropriate bureaucracy was attended to. From ordering the activity monitors to receiving all five took approximately four months. Future studies involving Gaehwiler activity monitors need to be planned well in advance.

6. Acceptability and reliability

The chapter 3 examined the acceptability of activity monitors to subjects with severe senile dementia and chapter 5 with a mixed sample of community living dementia patients. The monitors were found to be subject to damage by patients (five instances during all dementia studies). It is not known whether this damage was accidental or wilful, possibly because the monitor was perceived as an intrusion. The monitors were returned to the manufacturer for repair, and again,

this was a lengthy process. Mr Gaehwiler claimed to have modified the delicate accelerometer arm to be more robust and subsequently no monitor required a second repair. The monitors were well tolerated by most of the patients in these studies. This acceptance by around 85% of patients is probably sufficient for activity monitors to be of use for most research projects (individual case studies might sometimes present a problem).

A sample of healthy elderly controls all wore the monitor without major complaint of inconvenience. A few remarks were made about the size and weight of the monitor, although the nuisance was never sufficient to decide to remove the monitor. Presumably if one of the larger types of monitor had been purchased this would have caused more discomfort. This information is of use when considering the ethical implications of placing activity monitors on cognitively impaired subjects. Wearing an activity monitor is not intrinsically unpleasant, although of course each individual may react differently to this technology.

7. Assessment of validity by different types of data analysis

There are three major methods of reading the data provided by the activity monitors. The activity graphs of individual patients may be visually examined, the data may be collated and examined as diurnal patterns or the numbers generated for a given epoch may be used in statistical analysis.

The method of visual inspection relies on the validity of the graphs to show genuine activity levels. This may be assumed from manufacturing specifications and was found to be the case when used with a treadmill and compared to a raw activity measure (Chapter 2). It was shown in chapter 3 that the difference in activity graphs between a very active and a very inactive patient was easily

observed. Judgements about changes in activity in one patient across two conditions were examined in chapter 6. The visual interpretation of differences between activity graphs proved consistent between two observers. Visual inspection was shown to have good validity for detecting change or lack of change in activity levels in five out of six patients. Barer (1977) commented that the visual analysis of single-case study data is appropriate in applied settings because only marked effects have clinical significance.

The distribution of the data provided by the activity monitors was positively skewed for hourly values for the control and severe dementia samples. Hence the median values for the samples were examined for diurnal activity pattern in the controls and severe dementia sample. The severe dementia sample showed significantly lower activity values during the day and slightly higher activity values at night. Many of the dementia sample received medication, especially to assist with sleeping at night. However, while medication undoubtedly sedated some of the sample it would not have reduced agitation in others and other^s still will not have received any medication for agitation. The overall effect is that the median values are a reasonable representation of activity in an "average" severely demented hospital in-patient (that is, a patient with a nearly successfully treated agitation problem).

The most important conclusion from comparing the activity patterns of severe dementia sufferers and controls is that the dementia patients have very low average activity. This gives rise to the hypothesis that in many patients activity will drop as dementia progresses. Activity of the dementia patients has a reversed trend from the controls as it rises during the day, instead of falling. This may reflect a natural rise in activity (and perhaps agitation) as the day progresses or could be artificially induced, such as the wearing off of morning medication as the

day proceeds.

Cosinor analysis has been used by some authors to assess changes in circadian rhythm, in depressed subjects for example. This method of analysis proved unsuitable with the data collected in this work. The information provided by cosinor analysis includes data on the amplitude of the cycle, the size of difference between the bottom of the sinusoidal wave and the peak of the wave. This information may not be the most appropriate for assessing behavioural disturbance however. A small amplitude may mean a patient is inactive by day and night or it may mean a patient is continuously active by day and night. While both can be said to be abnormal in comparison to control data, the former instance of low activity might not be considered disturbed behaviour. Some of the patients examined during this work showed (on visual inspection) large amplitudes because they were very agitated by day but slept well by night, thus their diurnal patterns appeared nearly "normal".

Information provided by cosinor analysis on the acrophase (peak activity) can be determined fairly accurately by visual analysis in these data sets as reported above. Because of the limitations of cosinor analysis an alternative method of time series analysis was not sought, but activity level total counts were examined by conceptually separate epochs.

The epochs chosen were picked after the inspection of control patterns of activity. Due to the variations in bedtimes and times of rising of the controls the reliable "night time" was rather short ; only four hours from 2.00am -6.00am. Four hours was a convenient length of time for the morning and afternoon epochs. The evening epoch activity probably reflected differing bedtimes. Analysis of the epochs between severe dementia patients and controls, by non-parametric rank

statistics show the differences during the day to significantly different, as can be seen from the hourly medians graphs. Analysis by epoch values was the major method for assessing validity with behavioural ratings and for the examination of differences within a sample of mixed severity community dwelling dementia patients.

The validity of activity monitoring as a measure of disturbed behaviour in groups was assessed by comparing carers ratings to ranked activity values for the potentially relevant epochs. The rating scale developed for the study in chapter 3 was found to only contain one item with reasonable inter-rater reliability; that of "wandering or pacing". This correlated with evening activity in the severe dementia sample. This may have been because wandering or pacing behaviour became more pronounced through out the day to peak in the evening. Alternatively it may be that "wanderers" are left to last when it comes to putting patients to bed, because they are less likely to stay there. This would enlarge the difference in activity values between "wanderers" and "non-wanderers", due to the decrease of activity in the "non-wanderers".

Behavioural ratings and activity were compared in the group of mixed severity dementia patients. Of the various items pertaining to agitation, wandering, over-active, sleep disturbed and passive behaviours, only the agitation item ("fidgeting, unable to sit still, pacing, fingering objects") correlated significantly with any activity epoch value (afternoon). This suggests that activity monitoring may be a valid measure of excessive agitation which results in higher activity levels. However, there is sufficiently unaccounted for variance in activity in the small correlations that the combination of subjective identification of disturbed behaviour followed by objective activity monitoring may prove an improved measure.

The hypothesis of reduced activity being associated with increasing dementia severity was tested in the mixed sample. It was further postulated that this association would exist in patients who developed less or no agitated-type behavioural problems but that patients with active-disturbed problems would obscure the association. This was tested with regression analysis. Most of the behavioural variables showed no impact on the relationship between cognition and activity. The hypothesis was supported when the behavioural variable was the disruption factor of the R-MBPC scale with the day time activity variables and for the wandering item with the night time variable. It was also true of the depression factor of The R-MBPC. This implies that the depression factor is measuring an associated aspect of behaviour to the disruption variables, as was demonstrated by the two factors' high inter-correlation. The amount of variance explained by the above model is low and the interaction between cognition, activity and behaviour is not clear. However, the association of increased activity problems with increasing cognitive impairment was maintained in this sample, as reported by Teri et al (1988), Rubin et al (1987a), Cooper et al (1989), Swearer et al (1989) and Burns et al (1990).

8. Future research

The 1987 CSO report of the Care of the Dementing Elderly suggested that the development of valid and reliable measures of behavioural disturbance was important to facilitate research into treatment strategies in dementia. Activity monitoring would provide an important additional measure of disturbed behaviour in studies of the efficacy of the use of hypnotics to control behavioural disturbance.

The study of drug withdrawal, reported in this thesis, was conducted with severe dementia in-patients only. This method was adopted in order to include patients already identified as agitated, since waiting for new referrals can be time consuming. In further studies, patients newly referred to psychogeriatricians with behavioural problems should be assessed for an improvement of behavioural disturbance within a treatment study. This method might also be more acceptable to family carers than a withdrawal study. It would also include a range of severities of dementia patients living in the community as this would include a greater range of types of behavioural disturbance

Behavioural intervention studies on the effects of ward routine and nursing practices on disturbed behaviour would also benefit from the use of activity monitors.

Increased miniaturisation of the monitors may increase acceptability to patients, over that which was observed in these studies (approximately 85%). A smaller lighter monitor might allow the instrument to be fixed immovably to a patient, ensuring it is not removed and lost. This would allow for longer term continuous monitoring of subjects. Longitudinal studies of small numbers of patients, over various time spans (for example, several months or several years), would provide valuable information about the changes of activity as they relate to the progression of dementia. Such an approach could be used to elucidate the question of whether activity changes in dementia are episodic in nature.

Future research into the validity of activity monitoring as a measure of disturbed behaviour could examine the contribution made by the combination of activity monitoring and behavioural ratings together. This could be achieved within the frame work of a treatment study, using a sensitive behaviour rating scale (one

with at least five possible rating points reflecting change for each item). One sample would be rated for change in behavioural disturbance by carers as usual, while a second sample would be rated by carers who have informed access to activity monitor graphs. If the information from the activity graphs provided additional information the inter-rater reliability of ratings in the latter sample should be increased.

Activity monitor data could be particularly useful for monitoring behaviour at times when the carer may be absent, such as at night. Although activity and not sleep *per se*, are measured by the monitors, dementia patients who are awake are not liable to remain inactive. The coexistence of depression in dementia can result in the phenomenon of early morning waking for which activity monitors would be an ideal measure. Activity monitors have a potential role to play in the service setting. Activity monitor graphs could be a useful addition to the information available to medical staff making decisions on individual patient care requirements.

9. Concluding comment

Activity monitors are a practical method for assessing activity in dementia patients at various stages of the disease. Activity monitor data by itself is not always a valid measure of **disturbed** behaviour but used in conjunction with subjective assessment of disturbance may prove an improvement on the use of behavioural ratings alone. The grouping of activity data for analysis incorporates too much unexplained variance in activity levels, although this would be improved by pre-selecting groups of patients who have been subjectively assessed as showing active-disturbed behaviours.. The visual analysis of activity graphs is a reliable and valid method of assessing activity change in agitated dementia patients. Used

in conjunction with carer assessment of behaviour, it should prove useful for monitoring behavioural change for clinical decision making.

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APPENDICIES

- I Dementia Activity Rating Scale

- II 1 Revised Memory and Behavior Problem Check-list
 2 Mini-Mental State Examination
 3 Clifton Assessment Procedures for the Elderly

- III 1 AB three days activity graph : first experimental condition
 2 AB three days activity graph : second experimental condition
 3 EW three days activity graph : first experimental condition
 4 EW three days activity graph : second experimental condition
 5 HG three days activity graph : first experimental condition
 6 HG three days activity graph : second experimental condition
 7 CL three days activity graph : first experimental condition
 8 CL three days activity graph : second experimental condition
 9 GT three days activity graph : first experimental condition
 10 GT activity graph : second experimental condition
 11 TM three days activity graph : first experimental condition
 12 TM three days activity graph : second experimental condition

- IV 1 Typical healthy elderly control subject three days activity graph-1
 2 Typical healthy elderly control subject three days activity graph-2

APPENDIX I

PLEASE NOTE: EACH RATER SHOULD USE
A SEPARATE SHEET AND
RATE INDEPENDENTLY.

Later

Subject

D/O/B

DEMENTIA ACTIVITY RATING SCALE

Please rate the patient for frequency of behaviours on the following scale.

- 0- Behaviour usually not present.
- 1- Behaviour infrequent / occurs on occasion but does not require special management.
- 2- Behaviour fairly frequent / occurs sufficiently often for staff to adopt a specific approach or tactic when dealing with the patient.
- 3- Behaviour very frequent / warrants a serious attempt at reducing behaviour through specialist intervention or treatment (e.g. drugs, physical restraint, behaviour modification).

1. Noisiness - Rate how much noise/speech the patient makes which is louder than necessary or is felt to be excessive in quantity.

☐

2. Irritability - Rate how irritable/hostile or aggressive the patient is with staff and other patients.

☐

3. Agitation - Rate the extent to which the patient indulges in repetitive, purposeless behaviour (except wandering)

☐

4. Wandering - Rate how much the patients wanders or paces without any apparant goal or purpose.

☐

5. Withdrawl - Rate the extent to which the patient lacks social responsiveness and interest in their environment.

☐

6. Sleep Disturbance - Rate how often the patient gets up or causes some disturbance during the night.

☐

PRE POST

MBPC-R

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened. Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY RATINGS:

- 0 = never occurred
- 1 = has occurred infrequently
(and not in the past week)
- 2 = has occurred 1 or 2 times
in the past week
- 3 = has occurred 3 to 6 times
in the past week
- 4 = occurs daily or more often

REACTION RATINGS:

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely

	Frequency	Reaction
1. Asking the same question over and over again	0 1 2 3 4	0 1 2 3 4
2. Trouble remembering recent events (e.g., items in the newspaper, on TV)	0 1 2 3 4	0 1 2 3 4
3. Trouble remembering significant events from the past	0 1 2 3 4	0 1 2 3 4
4. Losing or misplacing things	0 1 2 3 4	0 1 2 3 4
5. Wandering or getting lost	0 1 2 3 4	0 1 2 3 4
6. Unable to find way about indoors	0 1 2 3 4	0 1 2 3 4
7. Unable to find way about familiar streets	0 1 2 3 4	0 1 2 3 4
8. Not recognizing a familiar place	0 1 2 3 4	0 1 2 3 4
9. Not recognizing familiar people	0 1 2 3 4	0 1 2 3 4
10. Not recognizing a familiar object	0 1 2 3 4	0 1 2 3 4
11. Forgetting what day it is	0 1 2 3 4	0 1 2 3 4
12. Starting, but not finishing things	0 1 2 3 4	0 1 2 3 4
13. Difficulty concentrating on a task	0 1 2 3 4	0 1 2 3 4
14. Hiding things (money, jewelry, etc.)	0 1 2 3 4	0 1 2 3 4
15. Being suspicious or accusative	0 1 2 3 4	0 1 2 3 4
16. Expressing fearfulness, worry over imaginary or trivial problems	0 1 2 3 4	0 1 2 3 4
17. Destroying property	0 1 2 3 4	0 1 2 3 4
18. Doing things that embarrass you	0 1 2 3 4	0 1 2 3 4
19. Waking you or other family members up at night	0 1 2 3 4	0 1 2 3 4
20. Awakening early (before 5 am)	0 1 2 3 4	0 1 2 3 4

21. Reversal of sleep pattern (sleeping by day, up by night)	0 1 2 3 4	0 1 2 3 4
22. Trouble getting out of bed	0 1 2 3 4	0 1 2 3 4
23. Nightmares or fearfulness upon waking	0 1 2 3 4	0 1 2 3 4
24. Sleeping more than usual	0 1 2 3 4	0 1 2 3 4
25. Sleeping less than usual	0 1 2 3 4	0 1 2 3 4
26. Increased or decreased interest in sex	0 1 2 3 4	0 1 2 3 4
27. inappropriate sexual behavior (e.g. undressing in public)	0 1 2 3 4	0 1 2 3 4
28. Being constantly restless	0 1 2 3 4	0 1 2 3 4
29. Fidgeting, unable to sit still, pacing, fingering objects	0 1 2 3 4	0 1 2 3 4
30. Spending long period of time inactive	0 1 2 3 4	0 1 2 3 4
31. Tired or fatigued	0 1 2 3 4	0 1 2 3 4
32. Slowness in movements (walking, eating, etc.)	0 1 2 3 4	0 1 2 3 4
33. Being constantly talkative	0 1 2 3 4	0 1 2 3 4
34. Talking loudly and rapidly	0 1 2 3 4	0 1 2 3 4
35. Talking in a very soft voice with little expressiveness	0 1 2 3 4	0 1 2 3 4
36. Talking little or not at all	0 1 2 3 4	0 1 2 3 4
37. Appears anxious or worried	0 1 2 3 4	0 1 2 3 4
38. Engaging in behavior that is potentially dangerous to self or others	0 1 2 3 4	0 1 2 3 4
39. Threats to hurt oneself	0 1 2 3 4	0 1 2 3 4
40. Threats to hurt others	0 1 2 3 4	0 1 2 3 4
41. Aggressive to others verbally	0 1 2 3 4	0 1 2 3 4
42. Dwelling on the past	0 1 2 3 4	0 1 2 3 4
43. Reliving situations from the past	0 1 2 3 4	0 1 2 3 4
44. Talking about memories or unpleasant events or times in his/her life	0 1 2 3 4	0 1 2 3 4
45. Seeing or hearing things that are not there (hallucinations or illusions)	0 1 2 3 4	0 1 2 3 4
46. Grandiose, unreal thoughts about himself/herself (e.g. saying they are all powerful, or that they are God, etc.)	0 1 2 3 4	0 1 2 3 4
47. Eating sweets excessively	0 1 2 3 4	0 1 2 3 4
48. Not eating at all	0 1 2 3 4	0 1 2 3 4
49. Excessive appetite	0 1 2 3 4	0 1 2 3 4
50. Drinking	0 1 2 3 4	0 1 2 3 4
51. Smoking	0 1 2 3 4	0 1 2 3 4
52. Unpredictable giggling	0 1 2 3 4	0 1 2 3 4
53. Appears sad or depressed	0 1 2 3 4	0 1 2 3 4
54. Expressing feelings of hopelessness or sadness about the future (e.g. "Nothing worthwhile ever happens", "I never do anything right.")	0 1 2 3 4	0 1 2 3 4

55. Crying and tearfulness	0 1 2 3 4	0 1 2 3 4
56. Commenting about death of self or others (e.g. "Life isn't worth living", "I'd be better off dead.")	0 1 2 3 4	0 1 2 3 4
57. Talking about feeling lonely	0 1 2 3 4	0 1 2 3 4
58. Comments about feeling worthless or being a burden on others	0 1 2 3 4	0 1 2 3 4
59. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	0 1 2 3 4	0 1 2 3 4
60. Arguing, irritability, and/or complaining	0 1 2 3 4	0 1 2 3 4
61. Sighing	0 1 2 3 4	0 1 2 3 4
62. Clinging to caregiver, following and/or physically holding on to the caregiver	0 1 2 3 4	0 1 2 3 4
63. Complaining about aches and pains, physical discomfort	0 1 2 3 4	0 1 2 3 4
64. Sitting alone	0 1 2 3 4	0 1 2 3 4

THE MINI-MENTAL STATE EXAMINATION

ORIENTATION

1. What is the

Year?

Score Points

— 1

Season?

— 1

Date?

— 1

Day?

— 1

Month?

— 1

2. Where are we?

Country?

— 1

County?

— 1

Town?

— 1

Hospital?

— 1

Floor?

— 1

REGISTRATION

3. Name three objects, taking one second to say each. Then ask the patient all three after you have said them. Give one point for each correct answer. Repeat the answers until the patient learns all three.

— 3

ATTENTION & CALCULATION

4. Serial sevens. Give one point for each correct answer. Stop after five answers. Alternative: Spell 'WORLD' backwards.

— 5

RECALL

5. Ask for names of three objects learned in Question 3. Give one point for each correct answer.

— 3

LANGUAGE

6. Point to a pencil and a watch. Have the patient name them as you point.

— 2

7. Have the patient repeat "No ifs, ands, or buts."

— 1

8. Have the patient follow a 3-stage command: "Take the paper in your right hand. Fold the paper in half. Put the paper on the floor."

— 3

9. Have the patient read and obey the following: "CLOSE YOUR EYES."
(Write it in large letters)

— 1

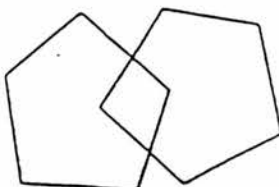
10. Have the patient write a sentence of his or her own choice. (The sentence should contain a subject and an object and should make sense. Ignore spelling errors when scoring.)

— 1

11. Enlarge the design printed below to 1.5cm per side and have the patient copy it. Give one point if all sides and angles are preserved and if the intersecting sides form a quadrangle.)

— 1

= Total 30



(see next page)

CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)

Behaviour Rating Scale

Name: Date of birth:

Current address/placement:

Please ring the appropriate **number** for each item

- | | | |
|--|---|---|
| 1. When bathing or dressing, he/she requires: | — no assistance | 0 |
| | — some assistance | 1 |
| | — maximum assistance | 2 |
| 2. With regard to walking, he/she: | — shows no signs of weakness | 0 |
| | — walks slowly without aid, or uses a stick | 1 |
| | — is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side | 2 |
| 3. He/she is incontinent of urine and/or faeces (day or night): | — never | 0 |
| | — sometimes (once or twice per week) | 1 |
| | — frequently (3 times per week or more) | 2 |
| 4. He/she is in bed during the day (bed does not include couch, settee, etc): | — never | 0 |
| | — sometimes | 1 |
| | — almost always | 2 |
| 5. He/she is confused (unable to find way around, loses possessions, etc): | — almost never confused | 0 |
| | — sometimes confused | 1 |
| | — almost always confused | 2 |
| 6. When left to his/her own devices, his/her appearance (clothes and/or hair) is: | — almost never disorderly | 0 |
| | — sometimes disorderly | 1 |
| | — almost always disorderly | 2 |
| 7. If allowed outside, he/she would: | — never need supervision | 0 |
| | — sometimes need supervision | 1 |
| | — always need supervision | 2 |
| 8. He/she helps out in the home/ward: | — often helps out | 0 |
| | — sometimes helps out | 1 |
| | — never helps out | 2 |
| 9. He/she keeps him/herself occupied in a constructive or useful activity (works, reads, plays games, has hobbies, etc): | — almost always occupied | 0 |
| | — sometimes occupied | 1 |
| | — almost never occupied | 2 |
| 10. He/she socialises with others: | — does establish a good relationship with others | 0 |
| | — has some difficulty establishing good relationships | 1 |
| | — has a great deal of difficulty establishing good relationships | 2 |
| 11. He/she is willing to do things suggested or asked of him/her: | — often goes along | 0 |
| | — sometimes goes along | 1 |
| | — almost never goes along | 2 |

12. He/she understands what you communicate to him/her (you may use speaking, writing, or gesturing):
- understands almost everything you communicate 0
 - understands some of what you communicate 1
 - understands almost nothing of what you communicate 2
13. He/she communicates in any manner (by speaking, writing or gesturing):
- well enough to make him/herself easily understood at all times 0
 - can be understood sometimes or with some difficulty 1
 - can rarely or never be understood for whatever reason 2
14. He/she is objectionable to others **during the day** (loud or constant talking, pilfering, soiling furniture, interfering with affairs of others):
- rarely or never 0
 - sometimes 1
 - frequently 2
15. He/she is objectionable to others **during the night** (loud or constant talking, pilfering, soiling furniture, interfering in affairs of others, wandering about, etc.):
- rarely or never 0
 - sometimes 1
 - frequently 2
16. He/she accuses others of doing him/her bodily harm or stealing his/her personal possessions — if you are **sure** the accusations are true, rate zero, otherwise rate one or two:
- never 0
 - sometimes 1
 - frequently 2
17. He/she hoards apparently meaningless items (wads of paper, string, scraps of food, etc.):
- never 0
 - sometimes 1
 - frequently 2
18. His/her sleep pattern at night is:
- almost never awake 0
 - sometimes awake 1
 - often awake 2
-
- Eyesight:
(tick which applies)
- can see (or can see with glasses)
 - partially blind
 - totally blind
- Hearing:
(tick which applies)
- no hearing difficulties, without hearing aid
 - no hearing difficulties, though requires hearing aid
 - has hearing difficulties which interfere with communication
 - is very deaf

Rated by: Date:
Staff/Relative

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Tenth impression 1988

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Printed in Great Britain for Hodder and Stoughton Educational a division of Hodder and Stoughton Ltd., Mill Road, Dunton Green, Sevenoaks, Kent, by CW Print Group, Oakwood Hill Industrial Estate, Oakwood Hill, Loughton, Essex IG10 3TZ.

CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)

Cognitive Assessment Scale

Name:

Current address/placement:

Date of birth: Occupation:

Information/Orientation

Name: Hospital/Address: Colour of British Flag:

Age: City: Day:

D.o.B. P.M.: Month:

Ward/Place: U.S. President: Year:

I/O Score

Mental Ability

Count 1-20 Time:.....Errors:..... Alphabet Time:.....Errors:.....

≤10 secs - no errors 3 ≤10 secs - no errors 3

≤30 secs - no errors 2 ≤30 secs - no errors 2

≤30 secs - 1 error 1 ≤30 secs - 1 error 1

0 0

Write name: Reading: (See overleaf)

Correct and legible 2 10 words or more 3

Can write but not correctly 1 6-9 words 2

Not able to 0 1-5 words 1

0 words 0

MAb Score

Psychomotor Time:..... Errors:.....

Pm Score

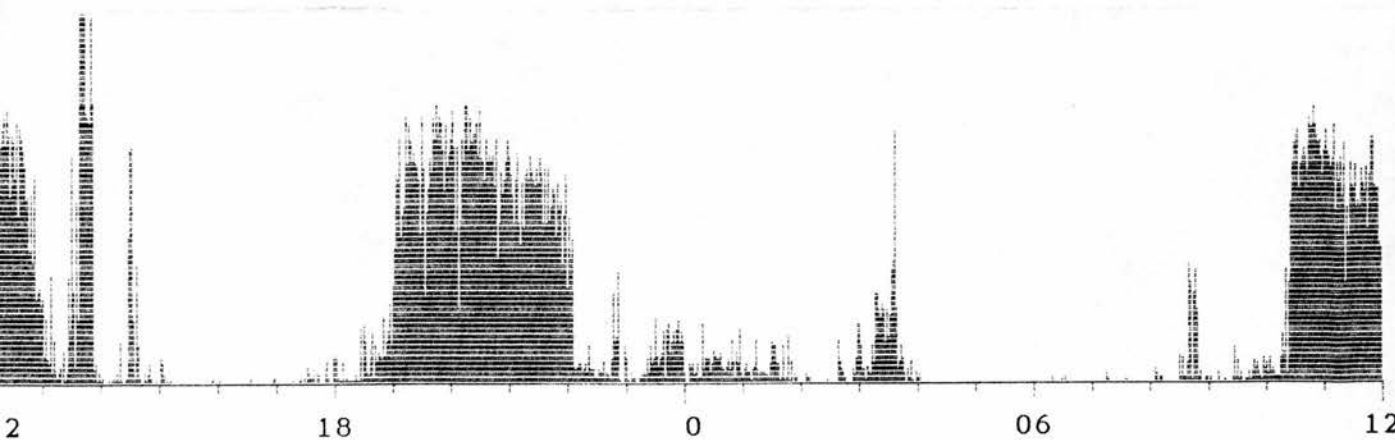
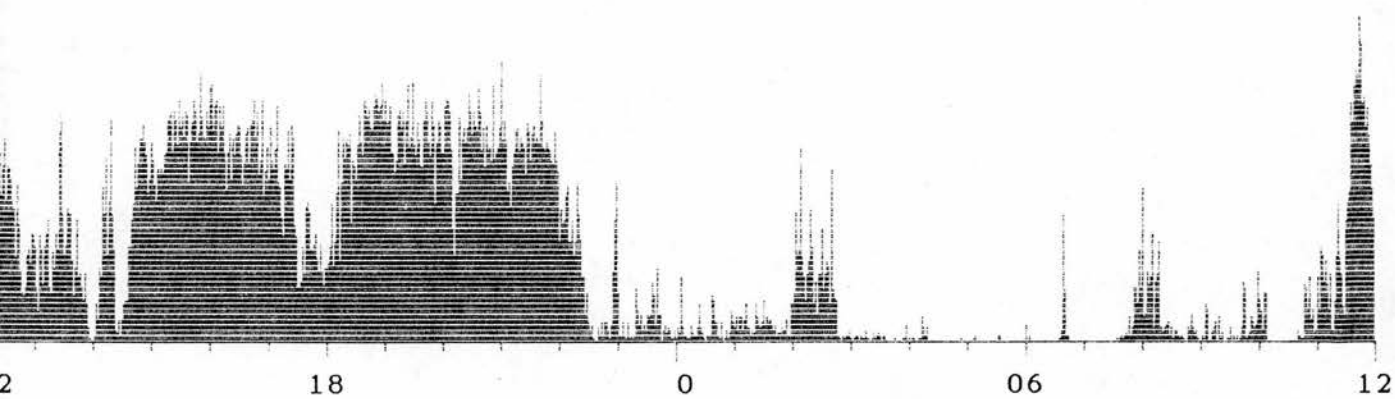
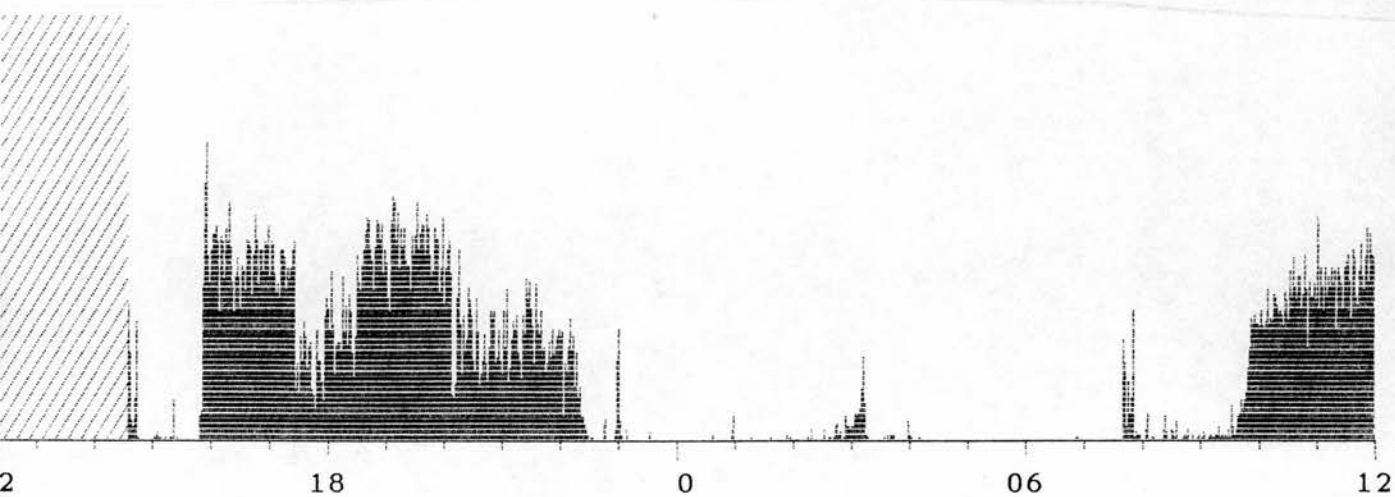
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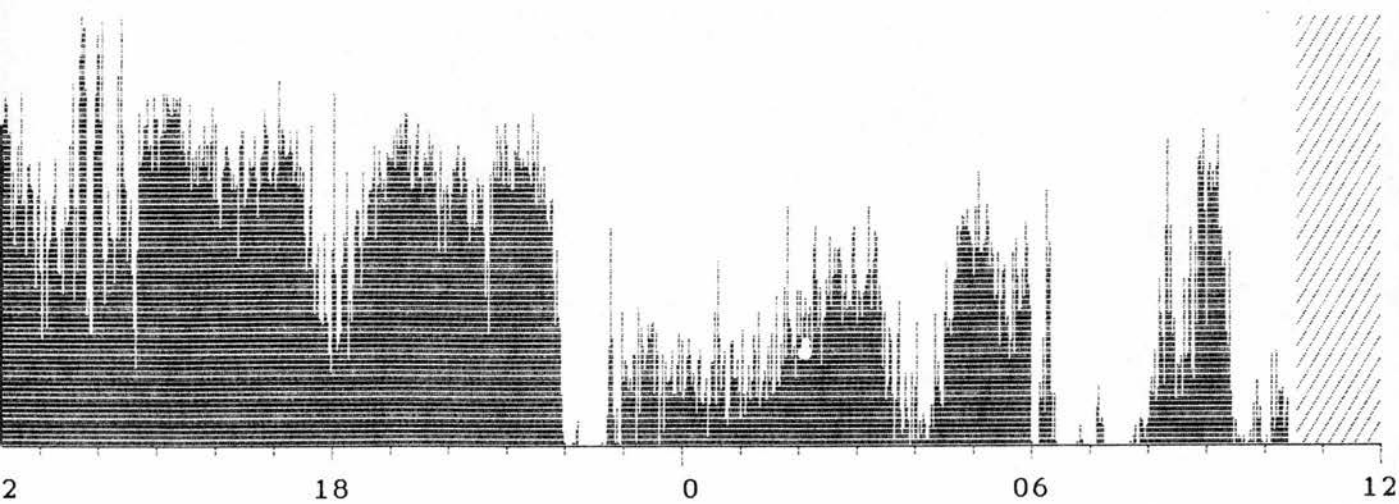
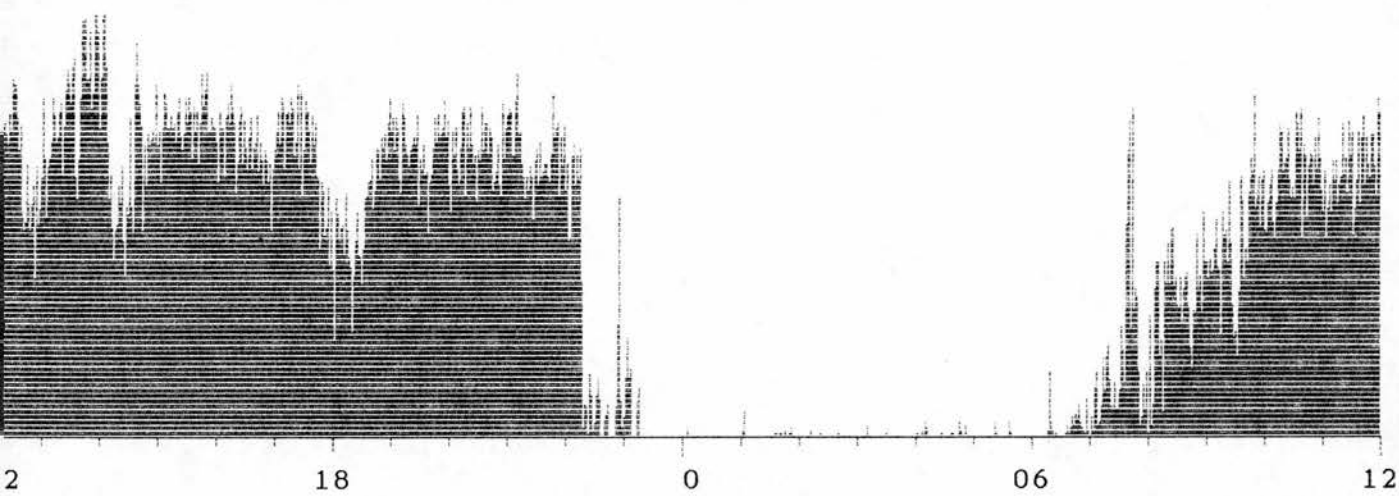
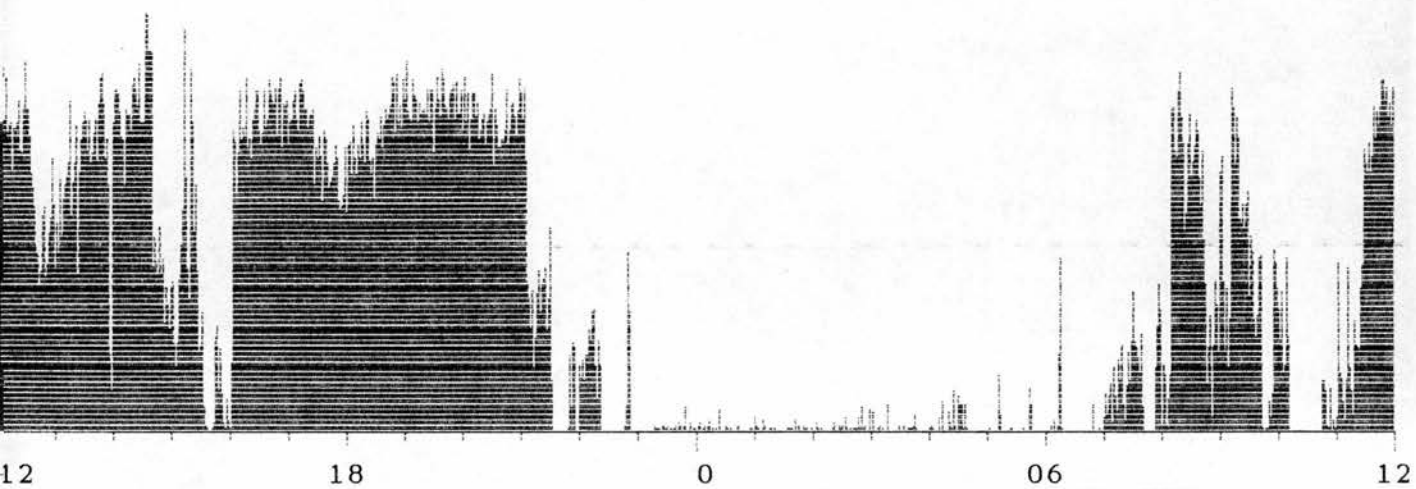
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Score: 10	9	8	7	6	5	4	3	2	1	0
Add Bonus 2 if 60 secs or under; 1 if 120 secs or under										

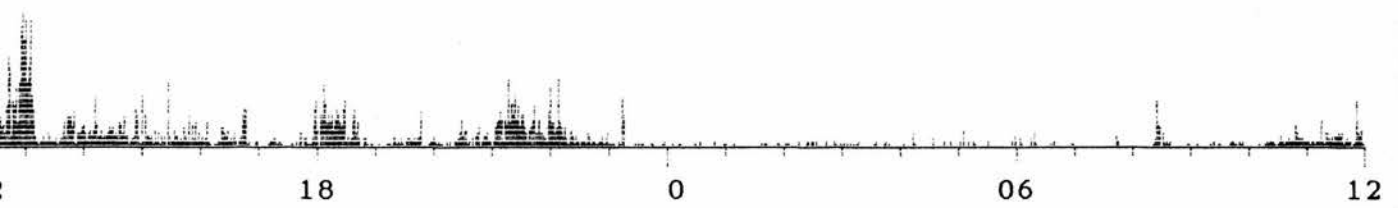
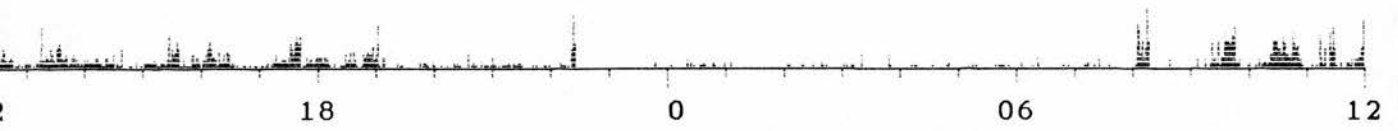
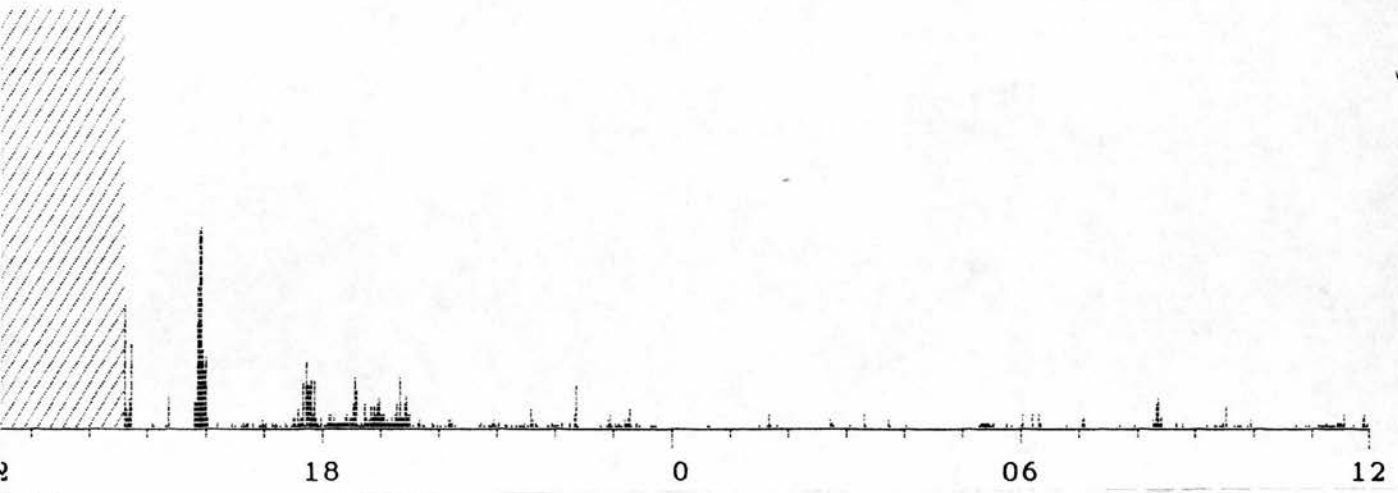
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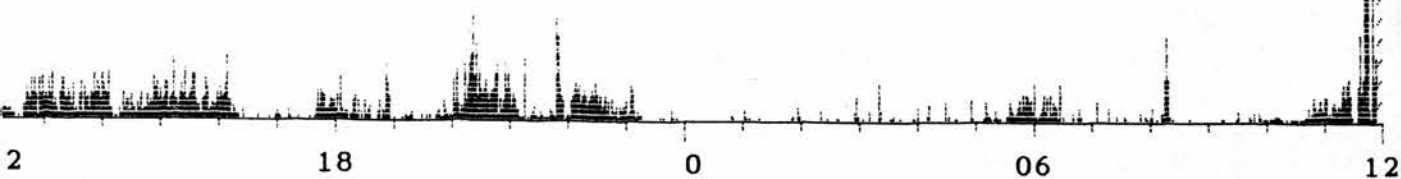
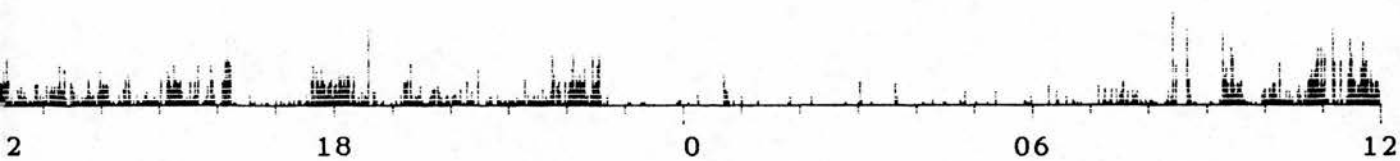
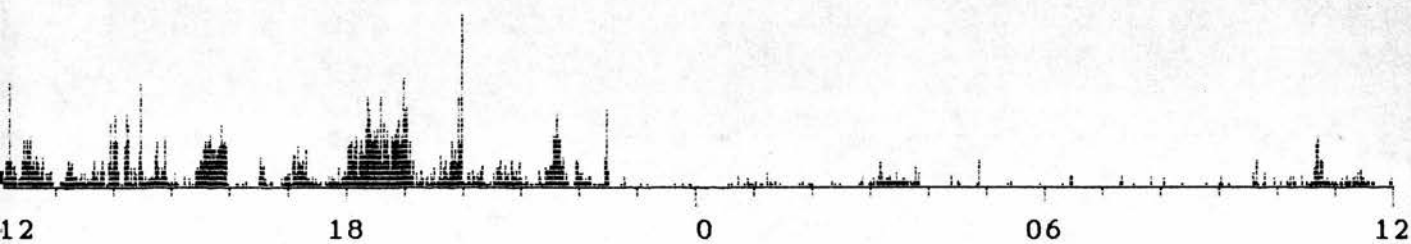
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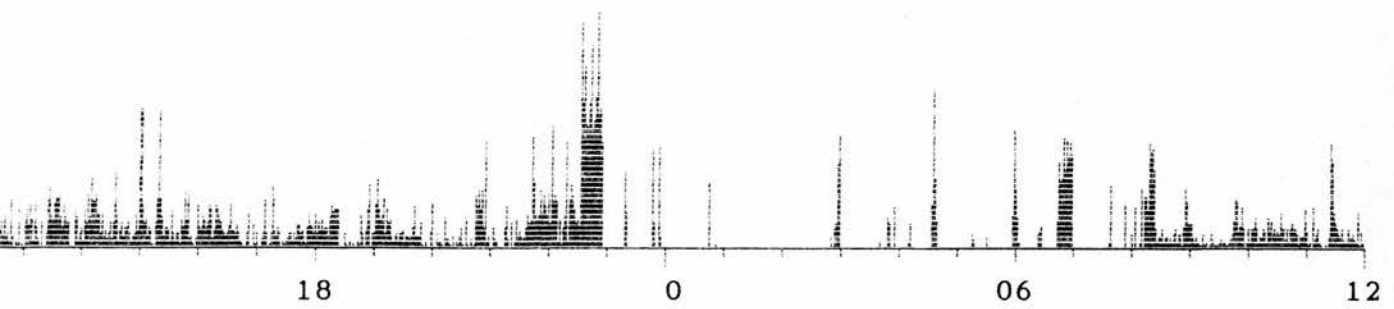
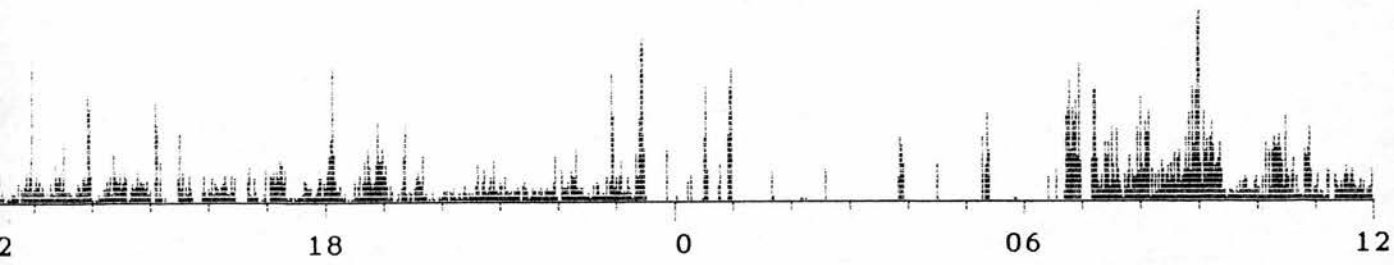
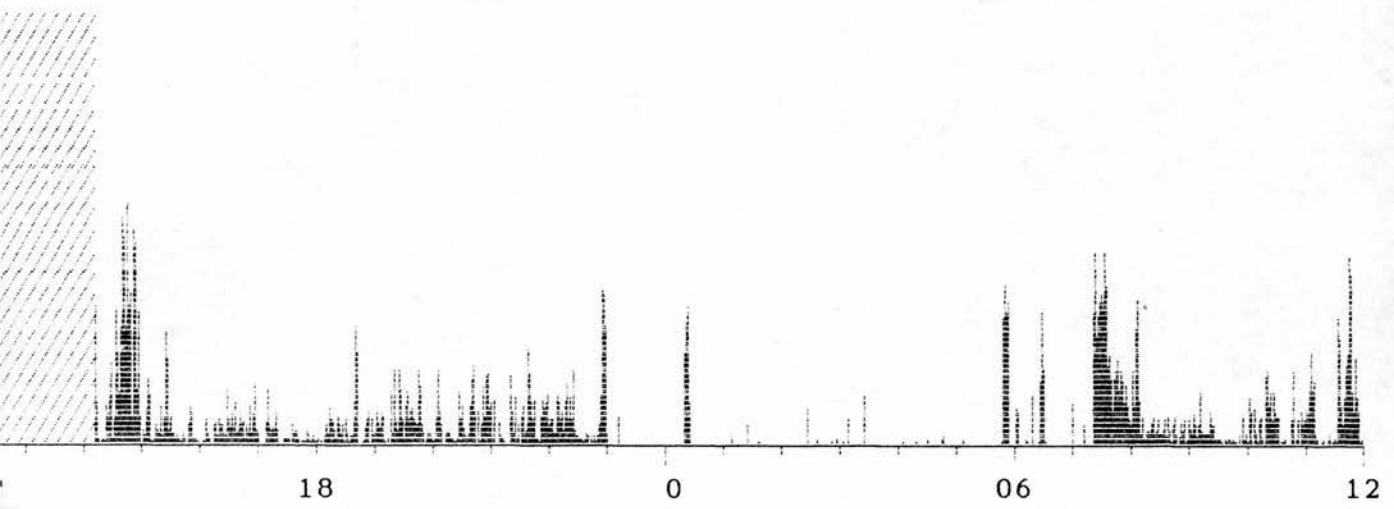
APPENDIX III - 1



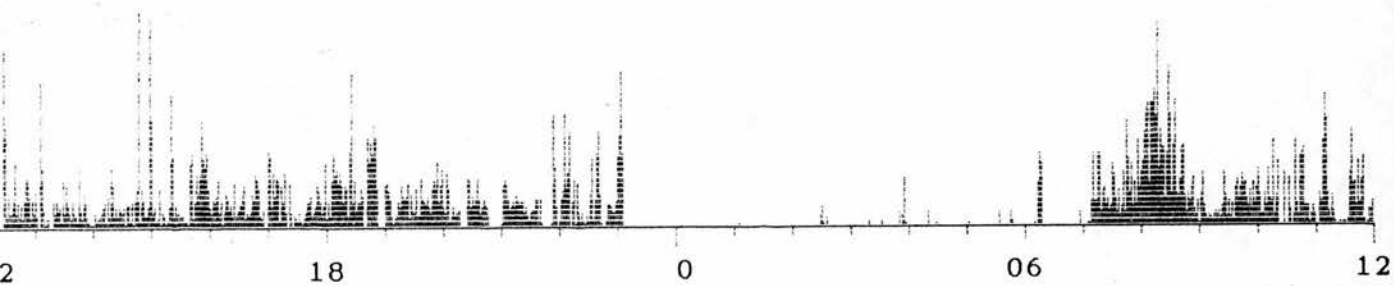
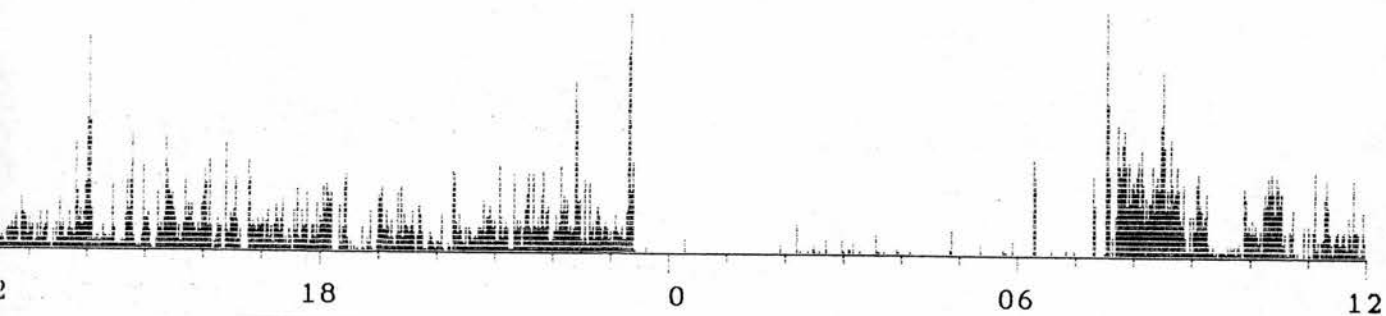
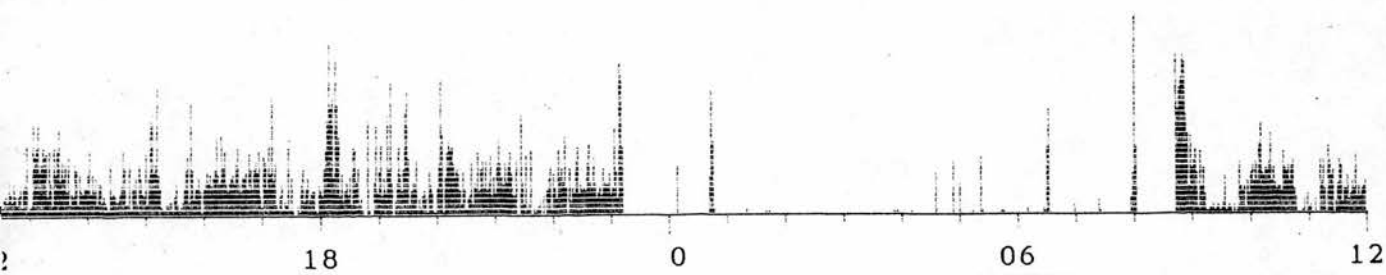


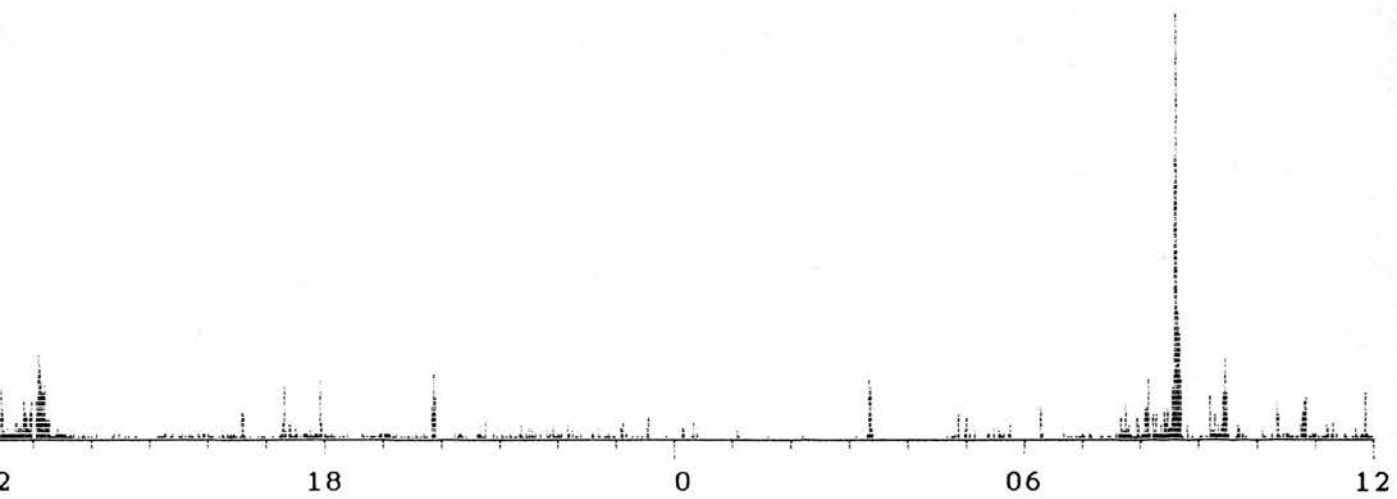
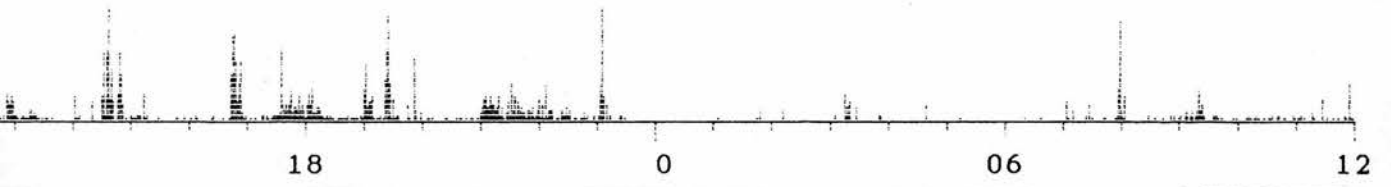
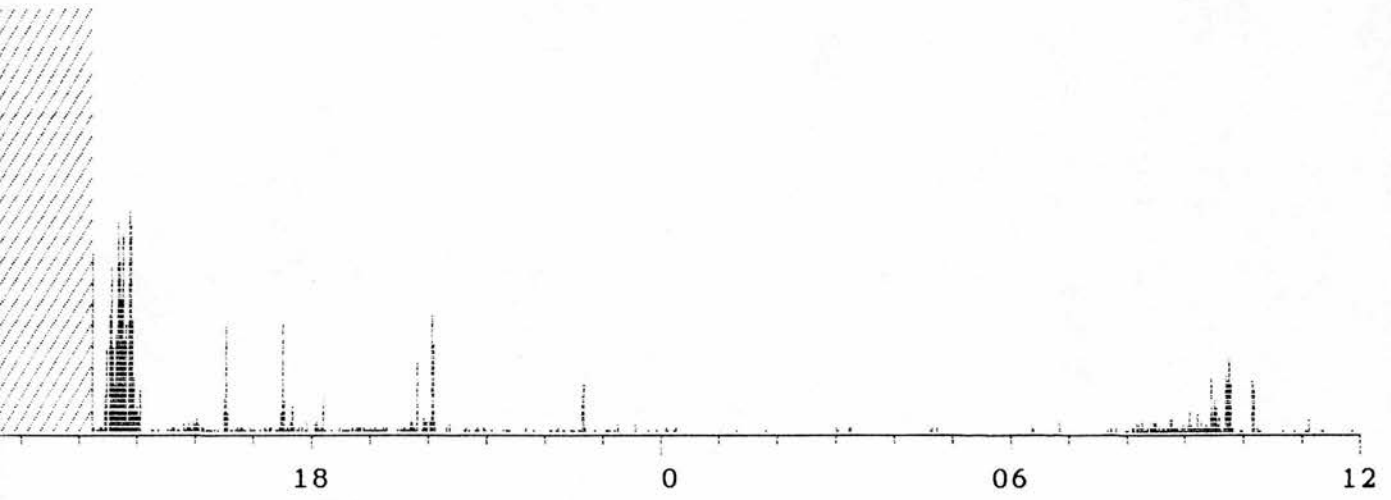




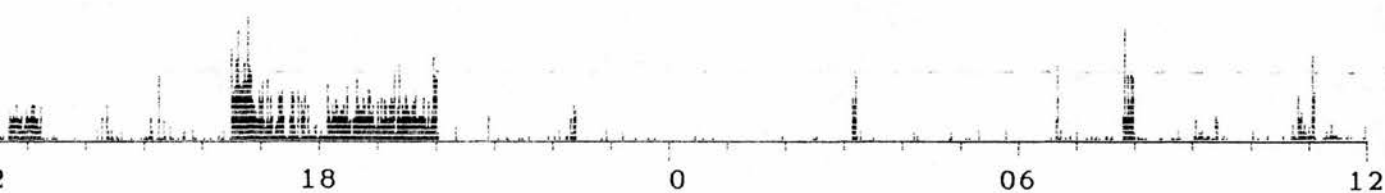
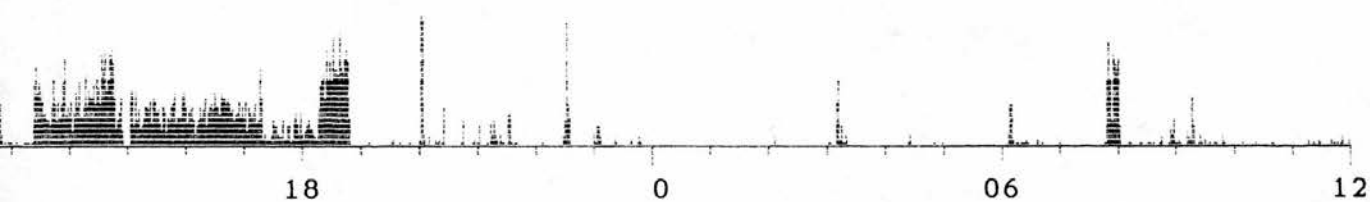
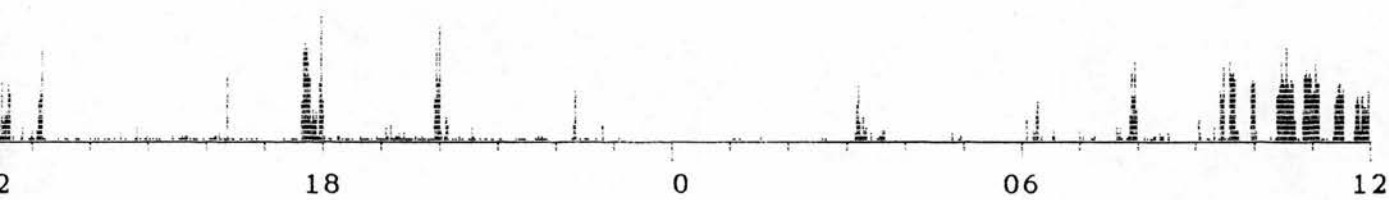


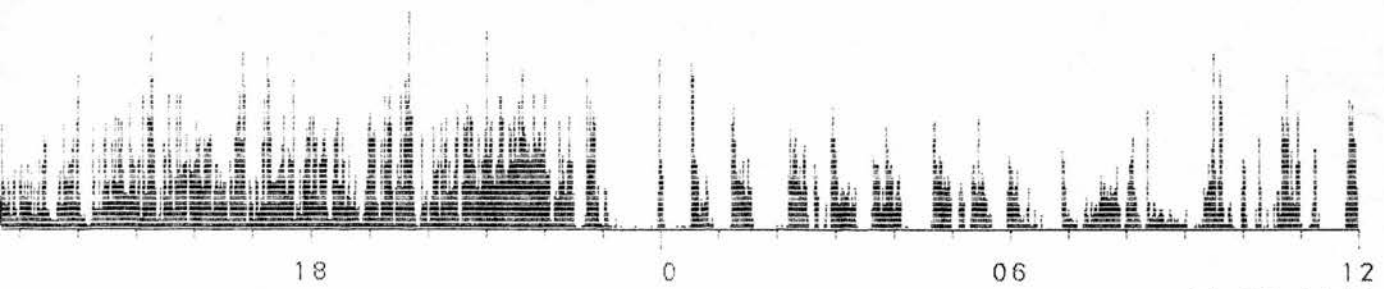
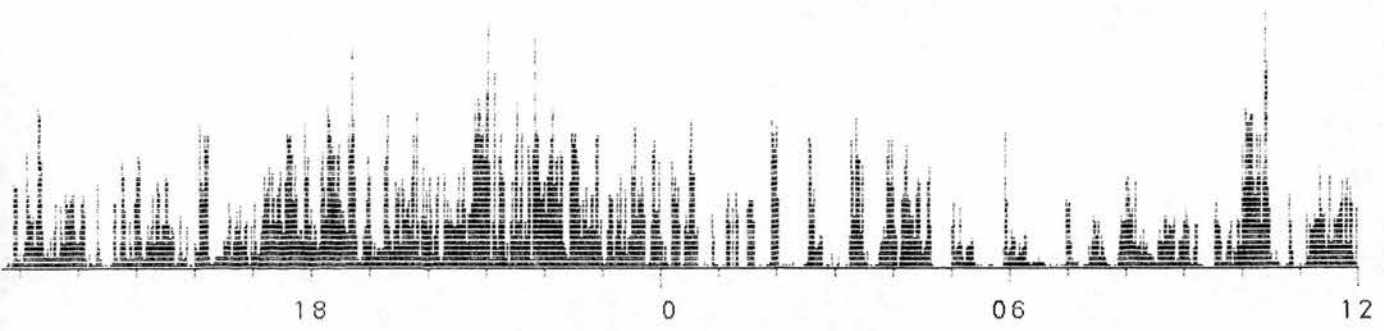
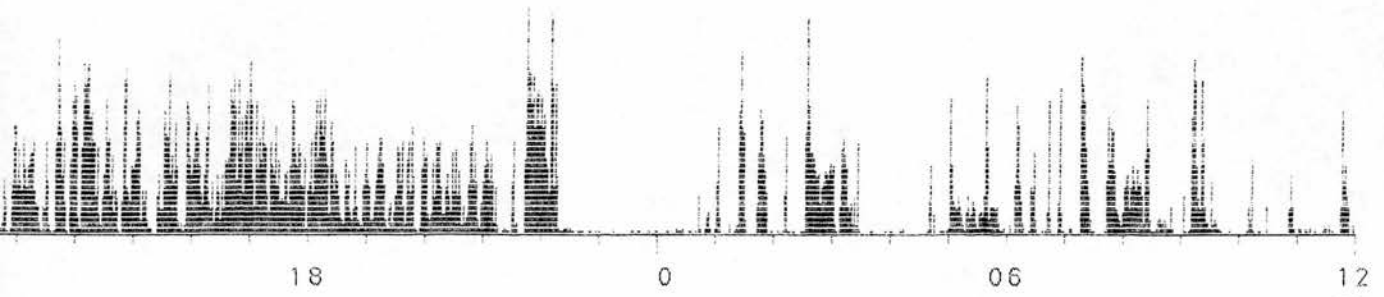
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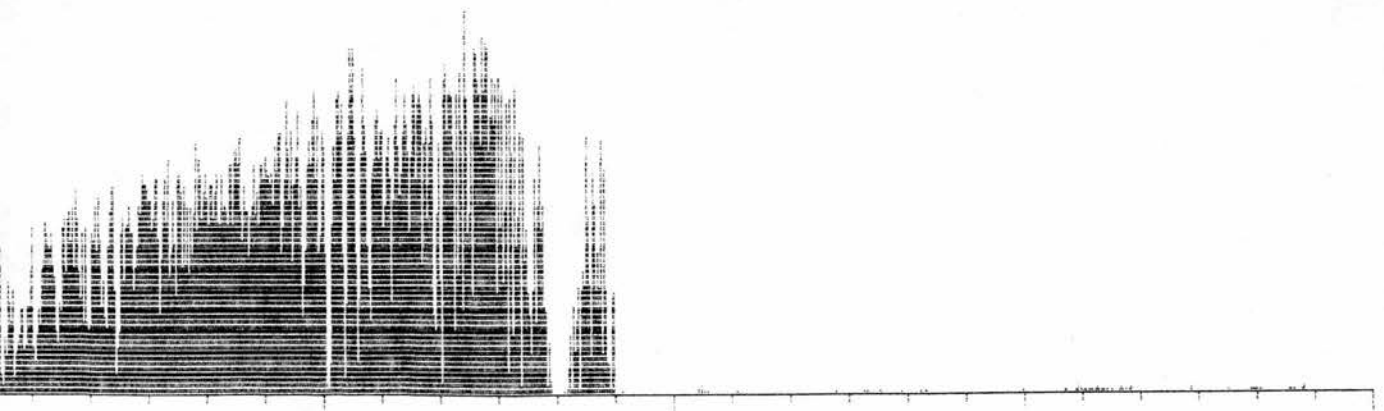
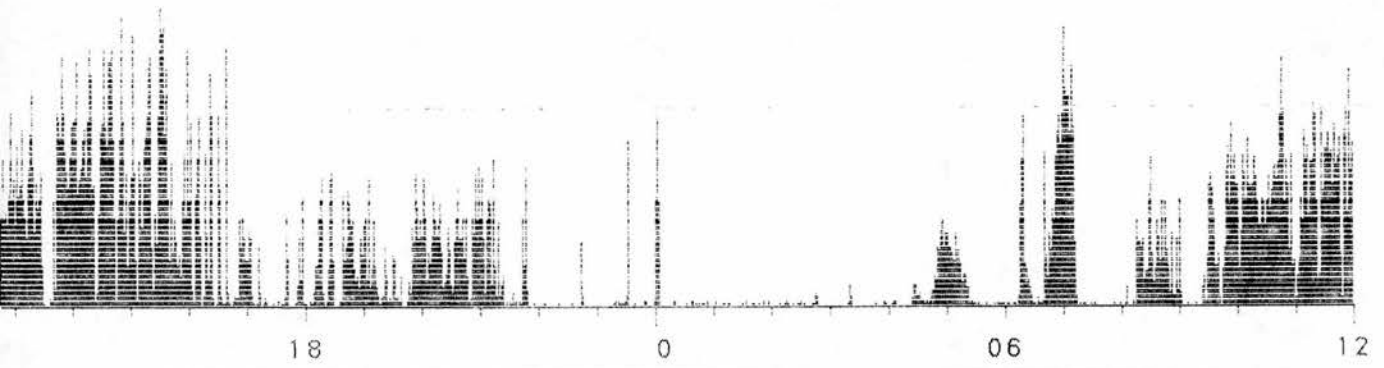




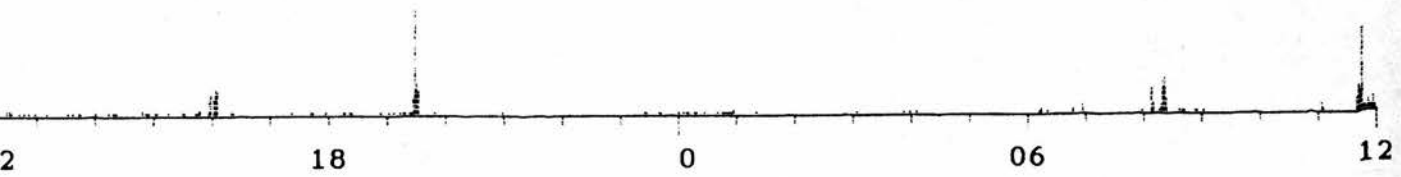
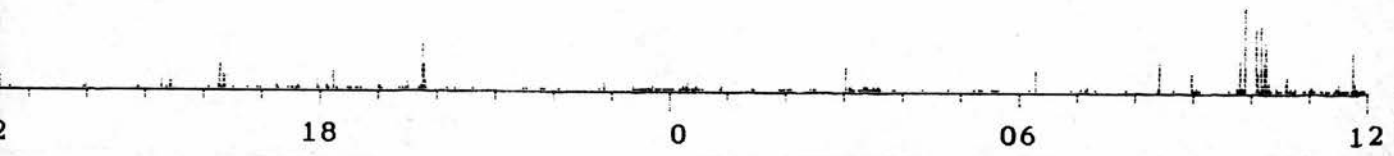
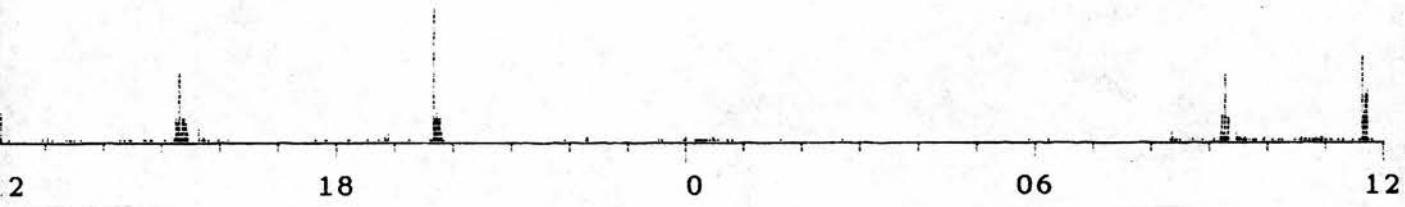
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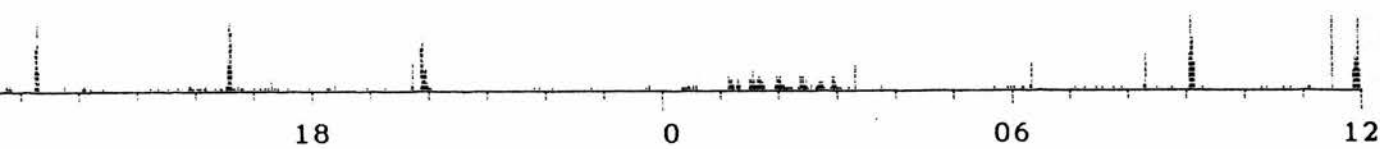
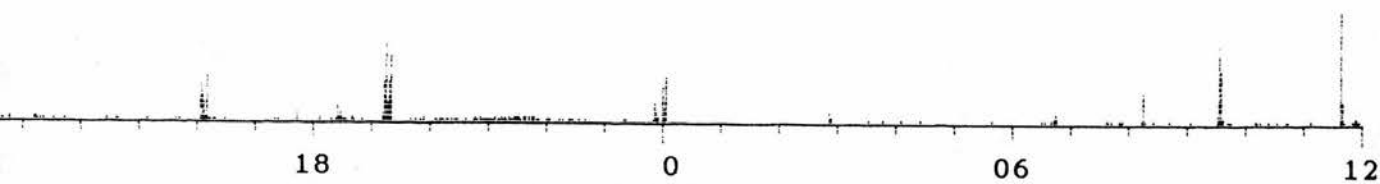
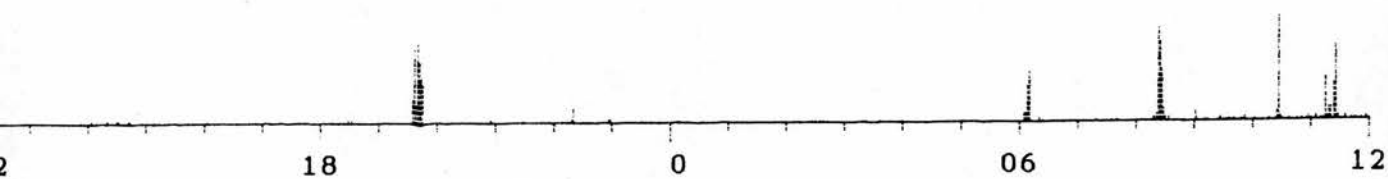




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APPENDIX IV - 1.

